Project PROJIMO

A villager-run rehabilitation program for disabled children in western Mexico

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About 140 million children in the world are disabled (more or less 1 in every 10). 120 million of these children live in developing countries. Most live in villages where no rehabilitation services or information is available.

It is sometimes argued that rehabilitation services for disabled children are too expensive, require too much sophisticated skill, and provide too limited benefit to be included in primary care at the family and village level.

We hope this report will help convince you otherwise. And we hope you will help meet its challenge.

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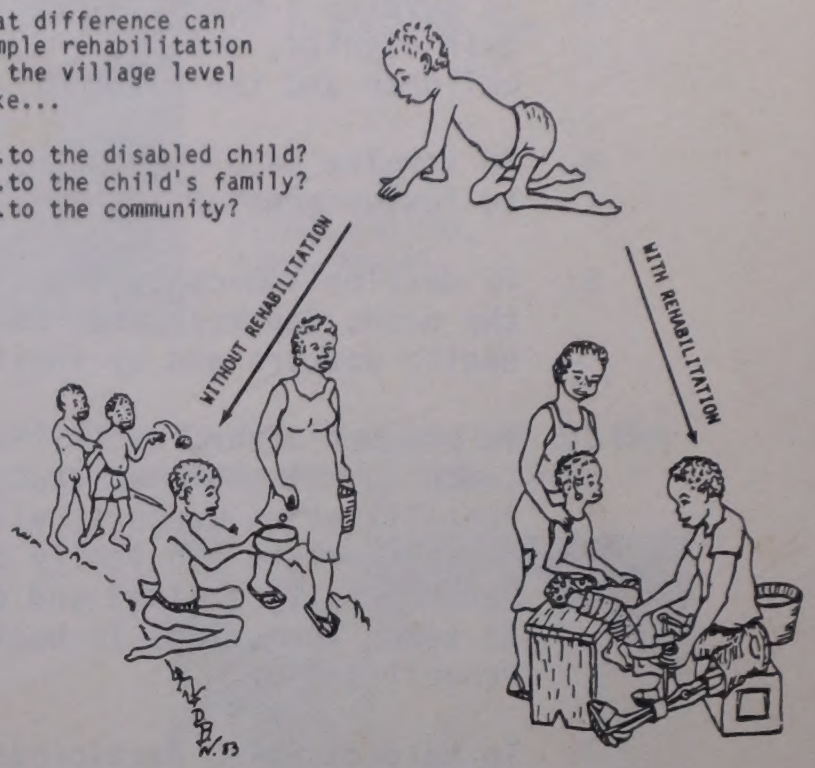
The need.

The need for an appropriate technology of rural rehabilitation is enormous. Severe physical disability affects the lives of millions of children and their families, mostly living in rural areas of developing countries. Polio, cerebral palsy, and deformities caused by accidents, burns and infections are among the most common causes. But most disabled children never receive the therapy, family guidance and orthopedic aids they need to develop their potential capabilities. The infrequent rehabilitation services that exist are mostly provided by expensive professionals in the cities--and even there they are available only to a fortunate few. There is a great need to simplify and extend the science of rehabilitation, physical therapy and orthopedic aids so that basic skills are widely available to community health workers and through them to the families of disabled children. The main care and service providers must not be costly, highly trained professionals, but rather family members and dedicated persons from local communities who are willing to work at a cost the poor can afford. The focus must shift from the costly urban clinic to the village home.


What difference can simple rehabilitation at the village level make...
...to the disabled child?
...to the child's family?
...to the community?
WITHOUT REHABILITATION
WITH REHABILITATION

What is PROJIMO?

Project PROJIMO in Western Mexico is a modest yet innovative response to this enormous need. It is a rural rehabilitation program run by local villagers, most of them disabled. The main purpose of the program is to give families the understanding and skills they need to help their disabled children develop their full potential. The project is structured to develop self-reliance in all who participate: workers, parents, and children. It is a 'community-based' program in so far as it is directed by local persons from poor farmworking families, and has the participation, in many different ways, from much of the community.

The staff of PROJIMO, mostly disabled villagers, pose with some of the disabled children.

What does PROJIMO mean?

PROJIMO is a Spanish word for neighbor, in the most kindly sense such as 'love your neighbor'. But P.R.O.J.I.M.O. is also an acronym standing for 'Programa de Rehabilitación Organizado por Jovenes Incapacitados de México Occidental', or 'Rehabilitation Program Organized by Disabled Youth of Western Mexico'.

The goals of PROJIMO

1. To set up an experimental rural rehabilitation center, organized and run primarily by disabled young persons, that provides simple orthopedic and rehabilitation services for physically disabled children.

2. To form a team of 'community rehabilitation workers' who take pride in serving the people, to the best of their ability, for wages as modest as those of the families they serve.

3. To develop a community setting that helps young disabled persons gain dignity, skills, and responsibility by helping other handicapped children and their families learn to cope and care effectively.

4. To involve people from the local village as a support system in order to foster greater integration and appreciation for the disabled.

5. To develop low-cost, simplified methods of rehabilitation adapted to the needs and resources of the rural area, and easily used by village health workers and by families of disabled children.

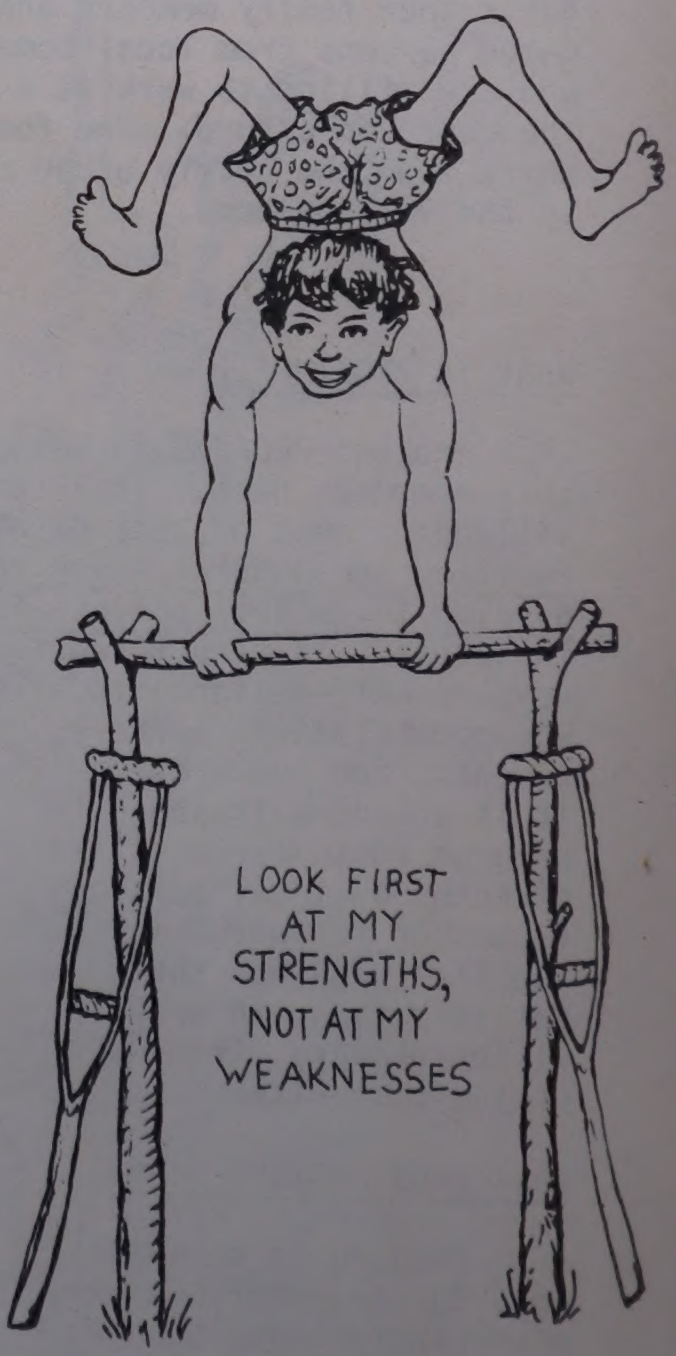
6. To produce clear, well-illustrated teaching materials so that community rehabilitation workers, village health workers and family members can be easily trained and continue to teach themselves in basic rehabilitation.

7. To help disabled participants to become self-reliant through production of low-cost orthopedic appliances, educational toys, and local crafts.

8. To conduct public educational activities, to promote the prevention of disability and the full acceptance of handicapped persons as equals and as persons who often have special abilities.

9. To evaluate, document, and share the developing PROJIMO experience in the hopes that it may help 'rural rehabilitation' become an integrated part of community-based primary care in many countries.

10. To make the whole process as challenging, as fun, and as friendly as possible.



The challenge of PROJIMO is to take techniques of physical therapy and rehabilitation out of the urban clinic setting, and translate them into simple, low-cost activities in the village home.

Photograph:
Cheyne Walk
Spastic's
Centre

Physiotherapy to obtain head control, back strengthening, and use of both arms and hands together:

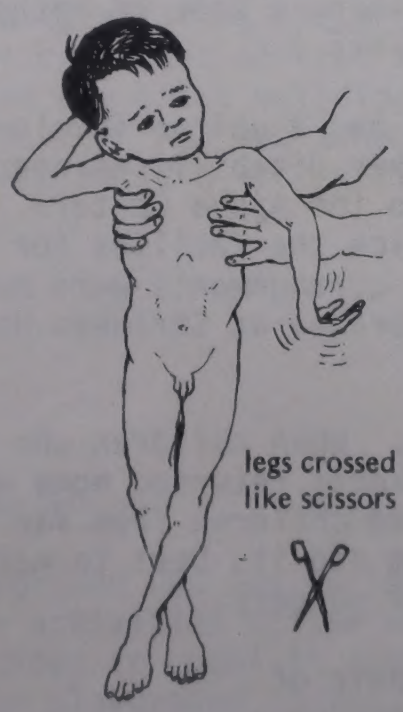
(a) in an urban clinic.

(b) in a village home.

Photograph:
Project PROJIMO,
Ajoya, Mexico

PROJIMO tries not only to adapt rehabilitation to the limitations of the rural situation, but also to its unique resources and possibilities. For example,

To help prevent 'knock knees' and scissoring of the legs in a child with cerebral palsy, the legs should be held apart as much as possible during early childhood.



Sitting on a log or with a pot between the legs helps to keep the child's legs extended.

Professionals in the cities recommend expensive orthopedic seats.

Villagers can make seats that provide the same help for free or at low cost.

But also, families can think of many other ways to keep their child's knees separated--ways that are fun and that permit the child to take useful part in daily family activities.

A simple seat of sticks like this can help prevent 'scissoring' of the legs in a spastic child.

Holes in the ground for his heels help keep his legs wide apart as he plays.

One of the biggest challenges to the PROJIMO village team is to 'deprofessionalize' rehabilitation--to find out how much of what is commonly thought to be the work of licensed practitioners (doctors, therapists, orthopedists, orthotists, prosthetists and rehabilitation engineers) can be done by laymen: by villagers and family members with lots of commitment but little formal education. There are no professionals on the PROJIMO staff. The village workers have picked up their skills through informal training and on-the-job learning. The team does invite professional therapists, orthotists, and rehabilitation engineers for short-term visits as teachers and advisers. But the program is run and the ongoing care is provided by villagers.

How and when did PROJIMO get started?

Planning and preparation of PROJIMO began in 1981 and the project was unofficially opened in September, 1982. However, a long history of community-based health activities preceded the new rehabilitation project, set the stage for it, and made the need for it clear.

For the past 18 years Ajoya has been the 'home base' of Project Piaxtla, a villager-run health care network. The local village team trains 'promotores de salud' (village health promoters) serving isolated mountain communities in a 10,000 square mile area. Project Piaxtla is an internationally known primary care program because of two widely used handbooks that have drawn on the Piaxtla experience (Where There Is No Doctor, a village health care handbook and Helping Health Workers Learn, a book of methods aids and ideas for instructors of village health workers.)

Even in its early years, Piaxtla had a unique involvement with disabled children. Children with polio and other disabilities needing orthopedic surgery were occasionally brought into the Ajoya Center. The obstacles to getting the surgery in Mexico at a price the families (or Piaxtla) could afford proved too great. So in 1970, arrangements were made for selected children to receive free surgery and braces at Shriners Hospital in San Francisco, California.

This was like rain in the desert. When children who had been dragging themselves around on their hands and knees returned home walking with crutches, the word spread rapidly. Soon disabled children from far and wide were arriving in Ajoya, and the health team did its best to make arrangements at Shriners for those in greatest need of surgery.

A problem soon arose with the repair of braces (calipers). Village children are very active. Frequently their braces break, or they outgrow them. To return them to Shriners for repair is not realistic, and to have them repaired by orthotists in the city is too expensive.

So in 1975 Piaxtla sent a village health worker, Roberto Fajardo, to study brace repair at Shriners. Roberto was the first of the village health workers to receive special training in rehabilitation.

As the years went by children with different disabilities continued to arrive at the health center. Some were taken to Shriners Hospital. But many had problems that did not require hospitalization or surgery. Some needed wheelchairs; some, artificial limbs; some, simple therapeutic exercises. The children's families needed advice on how to help their children become as independent as possible, despite their handicaps. But the village team lacked the knowledge and skills to do very much.

Jorge, before surgery at Shriners Hospital, had severe contractures (muscle shortening) following polio, which meant he could not walk.

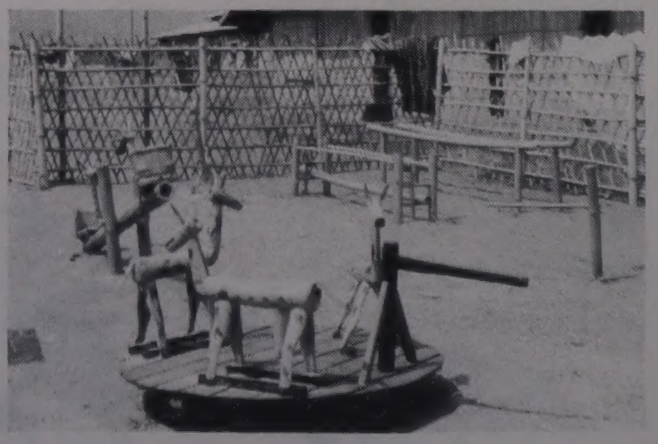
Finally, the village health workers came together to discuss what they could do better to meet the needs of the many disabled children who came to them. They decided to start a community rehabilitation program--if the villagers were willing. They called a village meeting and presented the idea. The community responded enthusiastically. Several women offered to provide room and board to visiting children and their families. Local craftsmen offered to help in converting an unused mud brick building into the rehabilitation center.* And the school children offered to help build a 'rehabilitation playground'.

Jorge a few weeks after surgery--the start of a new life.

The Rehabilitation Playground

Setting up a playground was one of the first and most visible activities of the new program. The team decided to model it after a bamboo rehabilitation playground in the Khao-i-dang refugee camp in Thailand. (David Werner had taken photos on a recent visit and shown them to the villagers.)

However, there was to be one big difference. The Mexican playground is for both disabled and able-bodied children. Local able-bodied children helped to make the playground with the understanding that they, too, would be allowed to use it. The team felt it was important that disabled and able-bodied children play together.



This rehabilitation playground in Thailand is based on designs of Don Caston.

* The building was purchased with part of a $5000.00 grant.

The children worked enthusiastically on the playground, which now is referred to affectionately by the villagers as 'El Parquecito'--or The Little Park.

First the village children went out on a truck to cut poles and vines from the local forest.

They brought back the poles and sticks to the playground area.

While some of the children cleaned the grounds, others began to make playground equipment.

This sloping rack they built helps children prevent or correct contractures (shortened muscles) that hold the feet in a tiptoe position.

Here the children make an enclosed swing.

This child with cerebral palsy had never had a chance to swing before, and was at first fearful.

But after trying out the swing, he loved it.

This swing, made of an old car tire turned inside out, is especially good for spastic children because it bends their back and shoulders forward.

One of the main purposes of the playground is to give parents of disabled children ideas for exercise aids and playthings they can make at home of local resources at almost no cost. Parents can try out different playthings with their child--those that the child likes, they can make themselves.

Old tires are used in a variety of ways--for swinging and climbing and development of balance.

Regular swings are placed beside the enclosed swings so that able-bodied and disabled children can swing side by side.

Children who can sit and hold on well--such as this spastic girl--can use a regular swing. This one is made from bamboo.

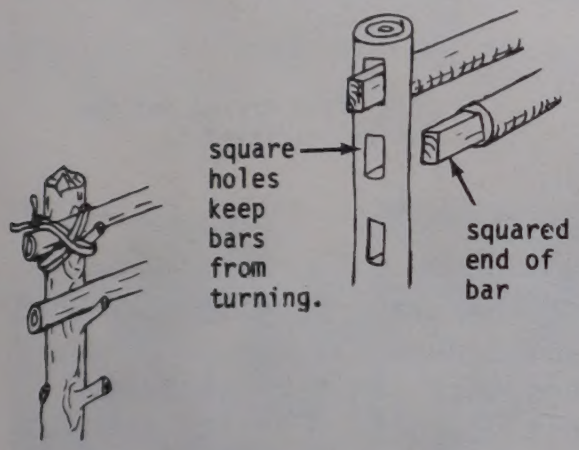
It spins!
It turns!
It rocks!
It swings!
Fun for the able-bodied, therapy and fun for the disabled.

The tire hanging low and flat is especially good for children with balance and control problems, who can begin to get a sense of moving using their hands.

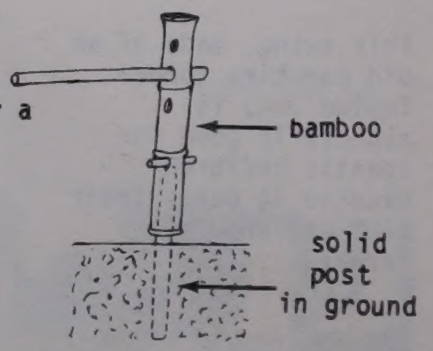
Parallel bars serve as gymnastic bars for abled-bodied children...

...and as aids in learning to walk for disabled children.

Height of parallel bars can be made adjustable.



Circular walker made of bamboo over a peg cannot be knocked over. It is useful for children with sudden uncontrolled movements.



A health worker and disabled rehabilitation worker made this simple 'rocking horse' out of an old stump.

Because the playground attracts both able-bodied and disabled children, they learn to play together. Here able-bodied children sport with disabled children in their wheelchairs.

A 'teeter-totter' in the crotch of a mango tree has a 'donkey' at one end. The other end has an enclosed seat for a disabled child. Behind this an able-bodied child can sit and help support the disabled child.

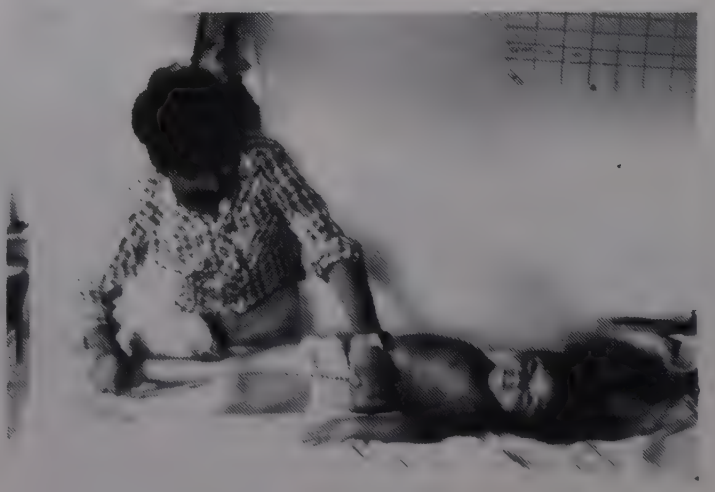
Disabled villagers often make outstanding health workers.

Roberto Fajardo is one of several village health workers of Piaxtla who are physically disabled, and who eventually became the founders of Project PROJIMO. As it turns out, the village health workers who happen to be disabled have often proved over the years to be among the best, most committed, longest lasting health workers in the program. Perhaps because of their own difficulties, these disabled health workers seem to have unusual sympathy for the illness and suffering of others. Even at risk to themselves, they will defend interests of the disadvantaged and oppressed.

Roberto Fajardo, now the coordinator of both the Primary Care Program (Piaxtla) and the Rehabilitation Program (PROJIMO), suffers from juvenile rheumatoid arthritis which began at age seven. He first came to Piaxtla at age 14, carried in on a stretcher. He was little more than skin and bones, and so disabled by arthritis that he could not sit up. Bones in his hands and feet had already begun to fuse.

Roberto Fajardo, a disabled village health worker, is now the coordinator of PROJIMO.

Roberto learned basic veterinary skills from a visiting veterinarian.



Here he measures the difference in leg length in a girl who had polio.

As a child, Roberto suffered a lot. He recalls the cold winter night when his grandmother took the blanket off him to cover the other children "because he was just going to die anyway."

It took the village team over a year to help Roberto regain reasonable use of his body. He stayed at the health center, and the team gave him 'chemotherapy' (medicine), 'physical therapy' (exercises), and 'psychotherapy' (love and understanding). As Roberto began to recover, they put him to work keeping records--then trained him in other skills ranging from pulling teeth to delivering babies to veterinary care. Roberto became a Jack-of-all-trades in health work, stayed with the program, and 8 years later (in 1980) became its coordinator.

Recruiting the project staff.

PROJIMO was started by disabled health workers from Project Piaxtla, with Roberto Fajardo as coordinator. They also invited disabled local villagers to join the team. In addition, they recruited two able-bodied craftsmen (one a blacksmith and leather worker, the other a welder and mechanic) to join, with the idea of teaching disabled workers their skills. David Werner, North American pioneer in village health care (also disabled) became the program adviser.

The PROJIMO work team began with 7 persons and gradually grew to 15 (10 disabled). Several of the new recruits were persons who first arrived for treatment, became involved, and later stayed on as workers.

Marcelo Acevedo at age 4. Disabled by polio, he lived in a village 2 days from the closest road. His older brother was also temporarily disabled when a tree fell on his leg.

Some of these persons, like Javier (below right), worked hard from the first. Others had never held a job before and needed a lot of coaching and support.

Project Piaxtla helped Marcelo get surgery, braces, schooling and trained him as a village health promoter.

Later Marcelo joined the PROJIMO team. He studied brace-making as an apprentice in two orthopedic shops in Mexico City.

Javier Valverde, who had surgery for foot deformities at Shriners Hospital, also studied brace-making at a San Francisco brace shop, and is now one of the leaders of PROJIMO. The team elected him 'outstanding worker of the year'.

Polo Leyva, disabled by polio, has never been to school, but has learned welding with PROJIMO and helps make wheelchairs.

Teenaged Ruben (on left), disabled by polio, first came for treatment and later joined the staff. Here he helps with record keeping. Ruben had never worked before. When he received his first pay, it was the happiest day in his life.

16 year-old Conchita, with cerebral palsy, first came for help learning to walk. Later she joined the team, especially to become the friend and helper to Teresa, a girl with juvenile rheumatoid arthritis. (See story at end of report.)

Adolfo Manjarrez studied wheelchair making in Nicaragua.

Don Ramon (on left), a local sandalmaker, disabled by an old bullet wound plus arthritis, is the oldest member of the team.

Volunteer help and community participation.

In addition to the more or less 'fixed' staff of PROJIMO, there are many other temporary workers and regular volunteers. Parents, brothers and sisters of children who stay for days or weeks with PROJIMO not only learn and assist with the therapy of the disabled child, but also help with clean-up and other projects. The disabled children themselves often help build equipment, games, and other things. Local craftsmen, schoolteachers, village women and children also drop by in their spare time, and help out in many different ways.

The brother of a disabled girl, Teresa, who learned to help with her therapy and cast-changing, helps make metal and plastic chairs which will be sold to support the PROJIMO team.

Villagers volunteering to put in a cement path for wheelchairs.

Community participation has been impressive. For example, shortly before the arrival of the first visiting therapist, over 60 villagers (mostly the men and older boys) put in a cement pathway to provide easy approach to the center by wheelchairs.

This 'therapy pool', built by the villagers, is a joyful gathering point for disabled and able-bodied children.

Rosa Salcido, village laboratory technician for Piaxtla and part-time worker for PROJIMO, has voluntarily cared for this child with club feet, while serial casts slowly straighten the feet.

Perhaps the biggest volunteer help is that provided by the house mothers who take disabled children from out of the area into their homes. If possible the mother or another family member stays with the child. But sometimes the child is left completely in the care of these village 'foster mothers'--which often means a great deal of extra work.

The village foster families are paid a small amount to cover extra food expenses, but the time and care they provide are donated.

Training.

The training of the village rehabilitation workers has been for the most part informal, through 'apprenticeship' and learning-by-doing.

Learning-by-doing is the educational approach of the village health team.

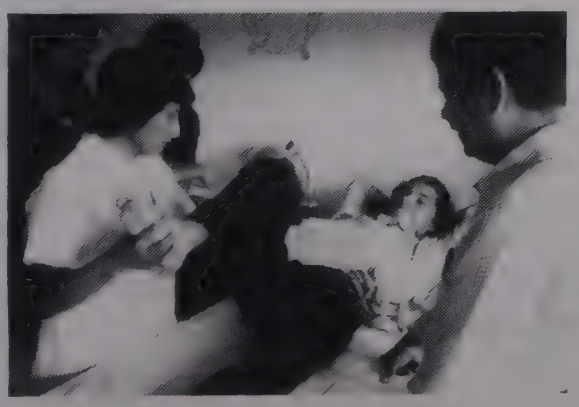
Opportunities have been sought whenever possible for the village workers to get appropriate training. So far the institutions and individuals who have provided training have done so on a volunteer basis. (PROJIMO has spent no money on actual training, although it does pay travel expenses for the visiting therapists.) Training opportunities have included:

- Learning outside the center:

• One disabled worker (Marcelo) has apprenticed in 2 brace shops (one plastic braces, the other metal braces) in Mexico City (1 month). Later he apprenticed with Rehabilitation Engineering and with the Center for Orthotics Design in Redwood City, California (1 month).

• Two disabled workers, (Roberto and Marcelo) have apprenticed in the brace shop at Shriners Hospital for Crippled Children in San Francisco (1 month each).

• 5 disabled workers took part in a UNICEF sponsored 'Simplified Rehabilitation' workshop in Toluca, Mexico (1 week).



Learners practice on Marcelo in Toluca workshop.

Javier tries out finger exercises during the Toluca workshop.

• One disabled worker (Javier) apprenticed at Hittenberger's Prosthetic and Orthotic Services in San Francisco (1 1/2 months).

• 2 workers (one disabled) apprenticed with Ralf Hotchkiss, an inspired wheelchair designer (paraplegic), at his shop in Oakland, California.

• One able-bodied craftsman villager (Salvador) apprenticed in a prosthetics workshop in the Khao-i-dang refugee center in Thailand, learning to make low-cost artificial legs using local resources (2 months).

• One able-bodied village craftsman (Adolfo) apprenticed making wheelchairs in Nicaragua with the ORD: Organization of Disabled Revolutionaries (6 weeks). There he also had a chance to learn with Ralf Hotchkiss who is an adviser to ORD.

Operation Handicap Internationale in Thailand trains amputees to make artificial limbs.

The most important learning of the team, however, has been the on-the-job learning right in the village center. Visiting professionals in various fields have volunteered to come to teach for a short time.

Under guidance of a visiting therapist, a rehabilitation worker practices exercises on a guest from the Philippines.

Here a visiting therapist, Ann Hallum, teaches hip stretching exercies to the older brother of a girl with cerebral palsy.

Ralf Hotchkiss during a teaching visit to Ajoya. Ralf got the idea for his wheelchair's front wheels (a large wheel rimmed by small rollers) from the Bible. The 4-wheel drive chair is designed for rough terrain.

Bruce Curtis, himself quadriplegic, visits PROJIMO as a counselor and adviser.

Learning at the village center from visiting professionals.

• The Physical Therapy Department at Stanford Medical School has an agreement with PROJIMO to make several teaching visits a year to Ajoya. Physical and occupational therapists from Stanford and the Valley Medical Center made 7 teaching visits from September 1982 to June 1983. On these occasions, disabled children for whom the team needed advice about therapy or rehabilitation were asked to come back. The health workers would review the children's problems, explain what they had recommended so far, and ask the therapists for criticism and further suggestions. In this way, the rehabilitation workers learned through actual practice--and so did the families of the disabled children.

• In addition to learning through attending the disabled children, when time allows (not often enough) therapists conduct 'classes' on basic therapy and rehabilitation. Even here much of the learning is 'hands on', with the learners practicing on each other.

• An orthopedic surgeon from Culiacan (the capital of Sinaloa, Mexico) visited and helped advise the team on orthopedic problems. He also performs free surgery for PROJIMO patients in special cases.

• Wheelchair designer Ralf Hotchkiss made a 10-day visit to Ajoya. During this visit he, Adolfo and Leopoldo built a new design of 'land rover' wheelchair for rough terrain.

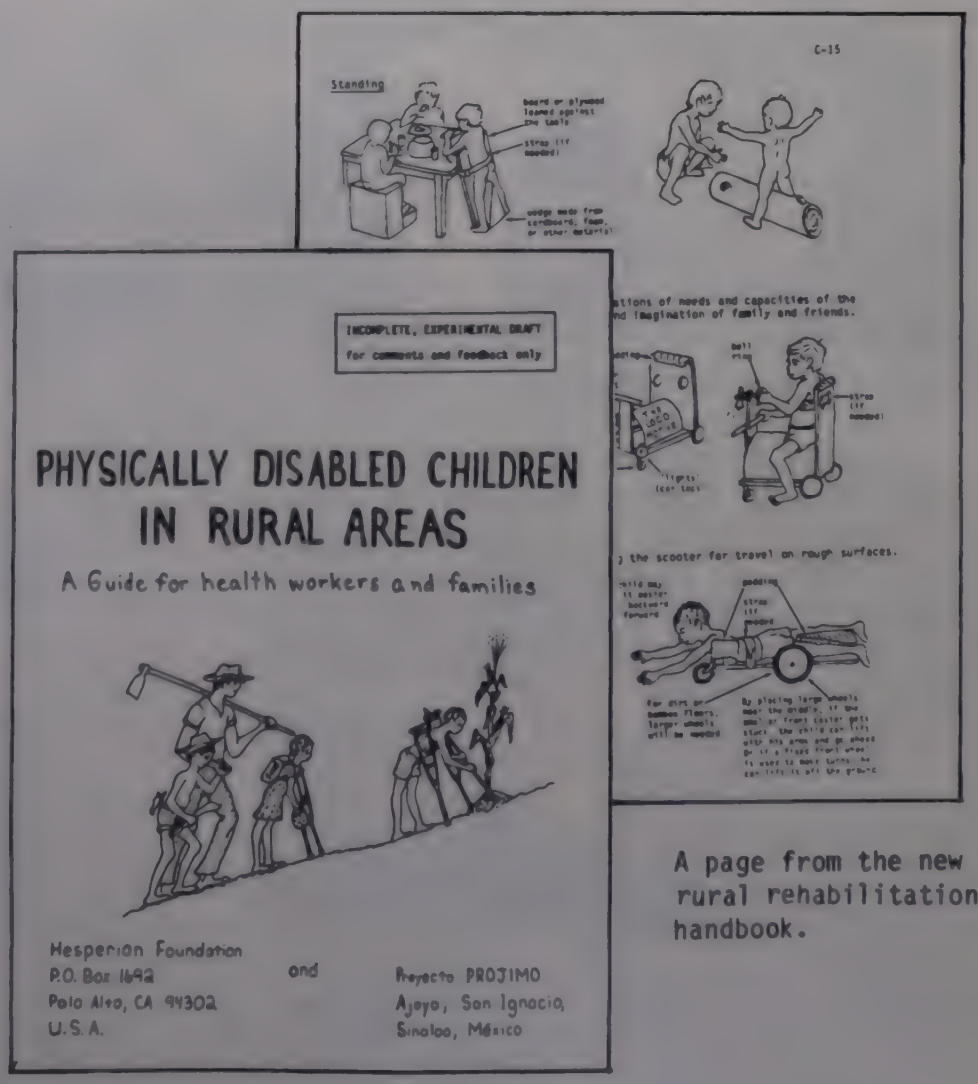
• Organizer and counselor of disabled persons, Bruce Curtis, has made two visits totaling 3 weeks. His role has been to help the PROJIMO team look at the personal and interpersonal needs of disabled persons--especially themselves--so that they can become better counselors to others. (Bruce also works with the ORD program in Nicaragua.)

A team of social workers from the University of Sinaloa in Mazatlán visited every Saturday for 3 months, to teach the team about interviewing, relating to, and communication with disabled persons and their families.

David Werner helps with a young disabled boy.

• Adviser David Werner acts as a gatherer and interpreter of ideas and scavenger of information for the PROJIMO team. He has brought back ideas from rehabilitation programs in many countries.

• To make key information more easily available to the village rehabilitation workers, David Werner, with the help of several therapists, has been working on a series of simply written, clearly illustrated instruction sheets. In time, these will be published as a sort of 'Where There Is No Physical Therapist'. Before publication, the rough drafts are being reviewed by therapists, orthotists, and rehabilitation engineers and sent to selected rehabilitation programs in various developing countries for review and criticism.



A page from the new rural rehabilitation handbook.

What kinds of things does PROJIMO do?

The main job of PROJIMO is to HELP FAMILIES OF DISABLED CHILDREN TO BECOME AS ABLE AND INDEPENDENT AS POSSIBLE IN HELPING THEIR CHILDREN IN WAYS THAT ARE INEXPENSIVE AND ENJOYABLE.

The PROJIMO team does (or is in the process of learning to do) the following:

It helps families learn more about the needs of their physically disabled children and how to meet them.

This means it does its best to:

--give advice on helping children become as self-reliant (non-dependent) as possible: through early stimulation, self-help skills, etc.

--teach family members simple therapy and exercises (in the form of games where possible) to help prevent or correct deformities.

--teach families what aids, equipment, and changes in the home they can make to help their children get around or function better.

--explain to families about prevention of disability so that they can become messengers to others.

--help bring families of disabled children together, to help, support, and learn from each other.

--make arrangements for disabled children and family members to stay with families in Ajoya while the team helps the child and family in aspects of rehabilitation. (This is important because most of the children come from outside Ajoya.)

In a class for rehabilitation workers and parents Miguel Zamora teaches the older sister of a disabled boy how to do hip-stretching exercises.

Roberto Fajardo teaches the father of a boy with polio how to repair and lengthen his child's brace. By learning to do this himself, the father becomes more self-sufficient in meeting his son's needs (and needs to spend less).

The PROJIMO village team performs basic (non-surgical) orthopedic procedures, such as correction of club feet and straightening of contracted muscles.

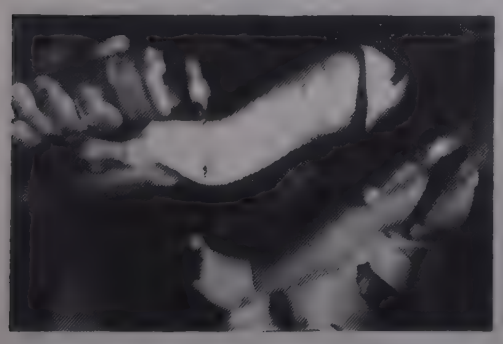
This child was born with club feet.

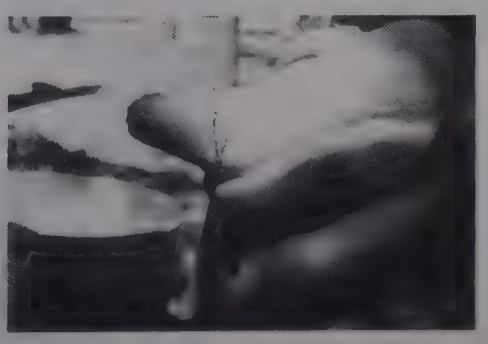
Under guidance from a visiting physical therapist, rehabilitation workers learn to straighten the feet through a series of casts (which takes several months).

BEFORE

AFTER

This little girl's club foot was completely corrected by the village workers in about 4 months.





When casting a club foot, first they correct the inward bend of the feet.

Then they gradually lift the foot by cutting out rings on the cast, closing the space, and holding it closed with a new strip of cast.

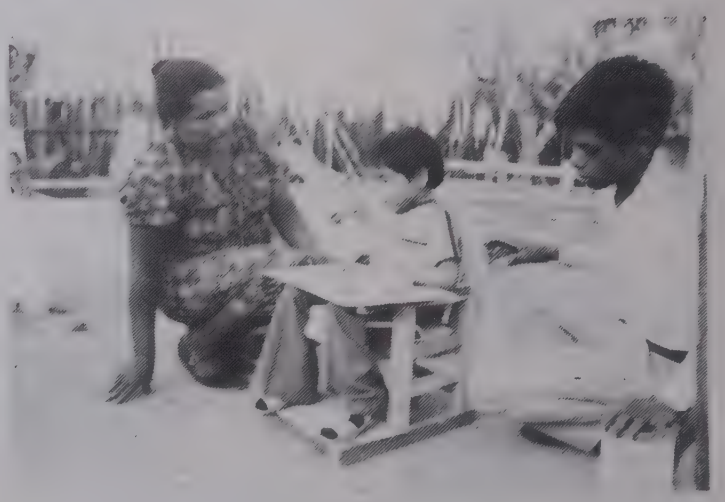
Series of casts are also used to straighten severe 'contractures' or shortened muscles which prevent a hip or leg from being straightened completely.

To save money, instead of buying plaster bandage material--which is very costly--the team makes part of its cast material out of cheesecloth strips and plaster of Paris. Here a village boy and Polo, a disabled worker, make bandage material.

The PROJIMO village team makes (or helps family members make) low-cost equipment and aids to help the children function better or become more independent. Here are a few examples.

Custom-designed seats

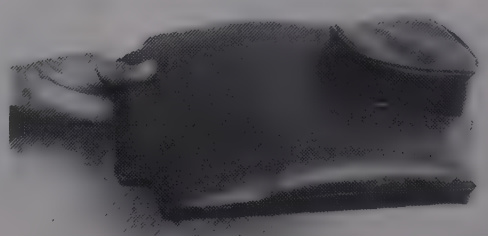
Camilo is severely spastic. He will never have much control of his back. He spends most of his life lying on his back. This special chair helps him be in a position where he can see what is going on around him.



This boy is also spastic. The chair, designed by PROJIMO workers, allows him to sit and provides space for play and eating.

When the cushion is removed, these chairs convert into a toilet.

The workers made a special cushion for the chair that holds his legs apart and is dipped in back to keep his front from slipping forward.



For severely handicapped children, 'toilet seats' can be built into specially designed chairs.

A cushion can be made to fit over the toilet seat for ordinary sitting.

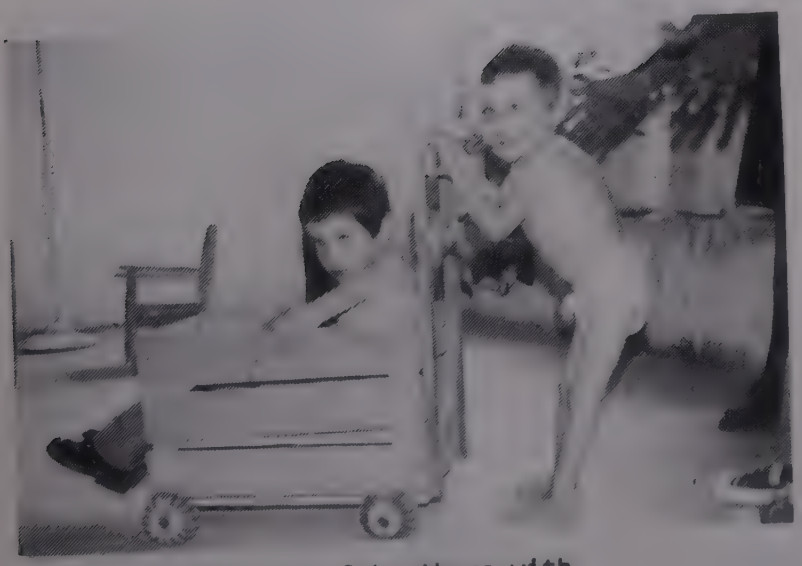
A shelf for the pot can be built in. Or the space under the seat can be left open so that the whole chair can be rolled over a toilet.

Special walkers

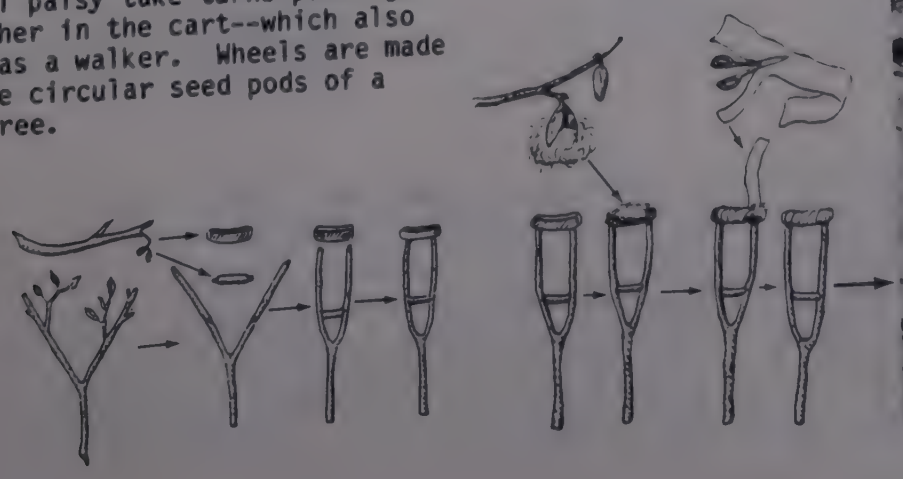
A walker like this with wooden wheels is simple to make and costs very little.

By comparison, this commercial walker cost the family of this child with spina bifida 1/3 of their year's earnings.

As it turned out, the child walked better (more upright) in these home-made bars than in the commercial walkers.



Making therapy fun: 2 brothers with cerebral palsy take turns pushing each other in the cart--which also serves as a walker. Wheels are made from the circular seed pods of a local tree.



Wheelchairs

Many disabled persons need wheelchairs and cannot afford them. Those that do have them often have chairs that poorly meet their needs or are so broken down they barely move. For villagers--or poor people from the cities who live on unpaved streets--no appropriate wheelchairs are available commercially.

For this reason, PROJIMO began to create rugged 'rough terrain' wheelchairs.

This young woman (who broke her neck when she slipped while carrying water on her head) arrived at PROJIMO in a wheelchair that was falling apart. The chair was tied together with barbed wire.

The folding wheelchairs built at PROJIMO are made out of standard steel pipe. Bicycle wheels are used, but extra-strong hubs are hand-made by the workers.

Building the rough terrain 'land rover' chair.

This chair with thick, heavy duty bike tires, can wheel over sandy, rocky ground that is impossible for an ordinary wheelchair.

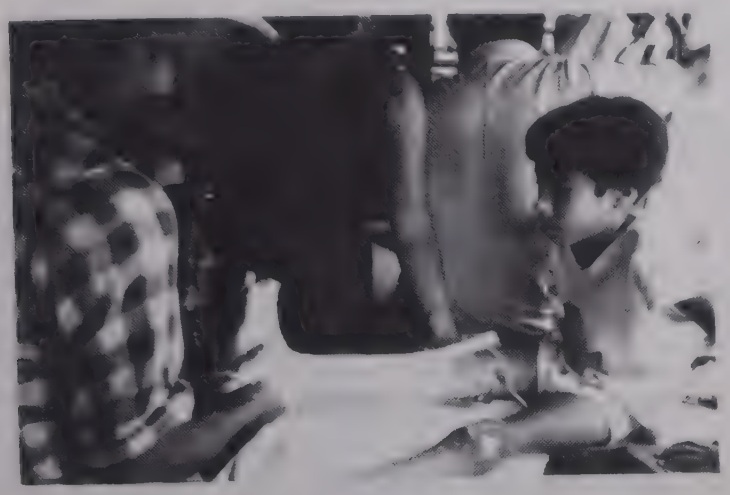
Wheelchair production is still experimental and slow. Also the cost, although less than commercial, is still beyond the reach of many families unless subsidized. With the help of engineer Ralf Hotchkiss, the team is working on ways to speed up production and lower costs. There is a long waiting list.

In the meantime, the PROJIMO workers have been able to repair and recondition many old wheelchairs that are brought in.

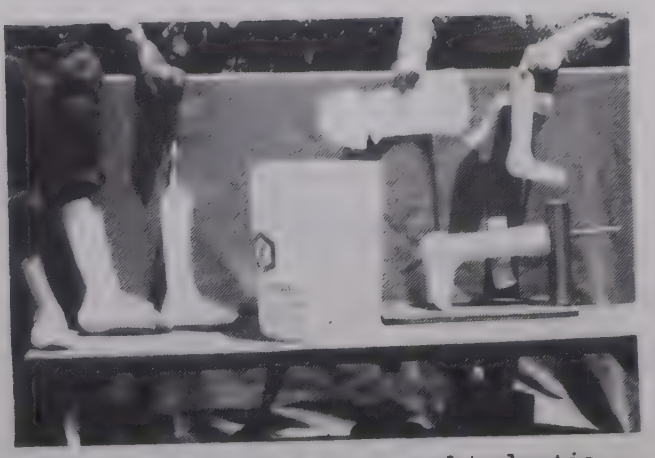
Also, families with wheelchairs and other orthopedic equipment they no longer need have begun to donate them to PROJIMO to repair and pass on to other children. This 'family to family' assistance is becoming one of the more important and inspiring aspects of the project.

Braces (calipers)

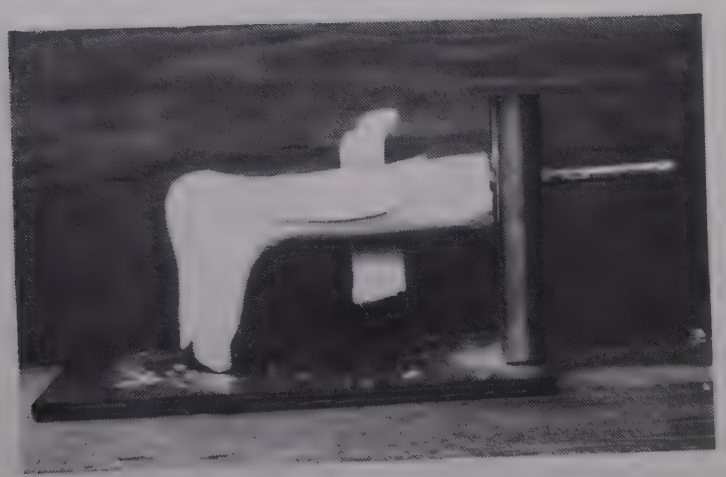
PROJIMO has been experimenting with ways to make low-cost lightweight braces, using mainly plastic.



Marcelo casts a child's leg--the first step in making a plastic brace.



One experiment has been to use old plastic buckets (the plastic being heated in an oven and shaped over a plastic mold of the child's leg). This picture shows the steps in making plastic braces from an old bucket.



Close-up of plastic on mold.

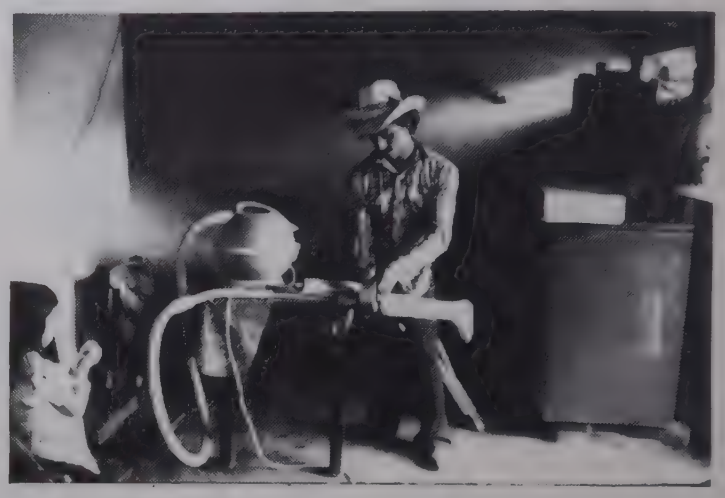
The completed plastic bucket braces.

This girl was prescribed a prefabricated plastic brace in Mexico by an orthopedic surgeon. It did not fit her well, but cost the family 6000 pesos--plus another 4000 because they had to buy it on credit (total = US$400.00 at time of purchase).

Developing low-cost alternatives for plastic braces is important. When purchased commercially (through orthotists or prescribed by government rehabilitation centers) plastic braces--even low-quality prefabricated ones--cost the family from US$200.00 to $400.00. By contrast, the plastic bucket braces end up costing about US$4.00 (labor of village rehabilitation worker included).

Repeated trials showed that the plastic-bucket braces work well as night splints, but soon break if the child walks on them. So the team now uses stronger 'polypropylene' plastic and a slightly more complex technology. The plastic braces (below knee) cost about $6.00 to produce and are of a quality equivalent to a $400.00 to $600.00 custom-made plastic brace in the U.S.A.

This child's knee doubles back severely. But he refused to wear the heavy metal braces that had been made for him. So Marcelo decided to make him lighter plastic braces.

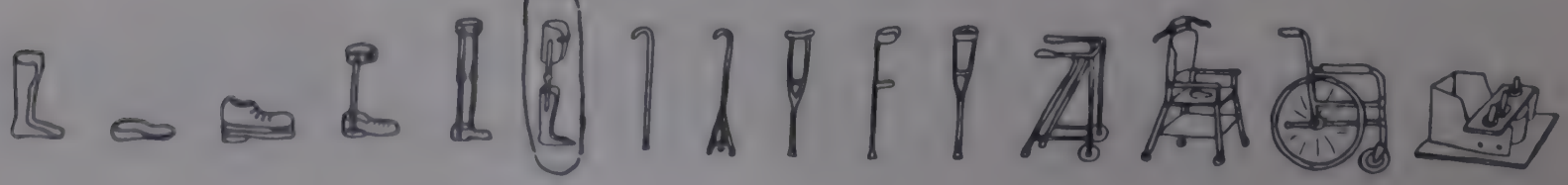


He attaches the plaster leg mold to an old vacuum cleaner in order to suck the air out from under the hot plastic. The plastic sheet is being heated in the metal box (homemade oven) on a neighbor's stove.

He wraps the soft hot plastic over the mold. After it cools he cuts the form of the brace, then attaches the upper part.

The boy liked his new light-weight braces and (as visits to his home have proved) continues to use them.

Aids made by PROJIMO:

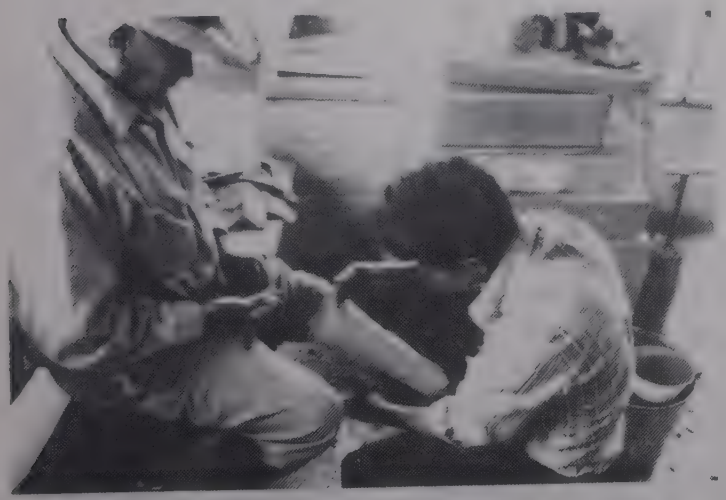


Artificial limbs (prostheses)

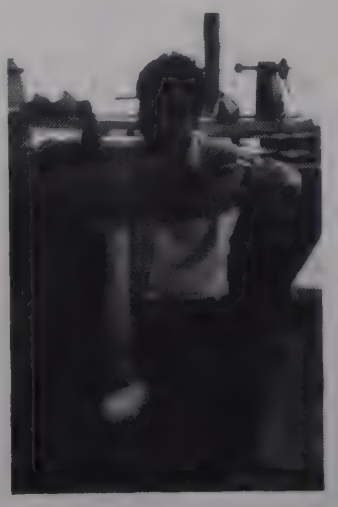
The challenge in producing artificial limbs is to make them at a cost poor people can afford. Within a month after PROJIMO began to make prosthetic legs, a request came from an orthopedic surgeon in the state capital asking if he could refer amputees to the village rehabilitation center to have their limbs made. He works in the Hospital Civil (poor people's hospital). Although high-quality modern prosthetics are available in the city, most of the amputees cannot afford them.

The artificial limbs (so far legs only) which Salvador makes are based on what he learned in Thailand. First a very low-cost temporary limb is made as follows:

Ruben adjusts a low-cost temporary limb to Jose's leg.



First Salvador makes a plastic cast of the leg.



Then he prepares a section of bamboo by splitting the upper part to form rays.

He bends the bamboo around the cast, wires it together, and coats it with a mixture of sawdust and glue.

Finally, he fits it to the man's leg.

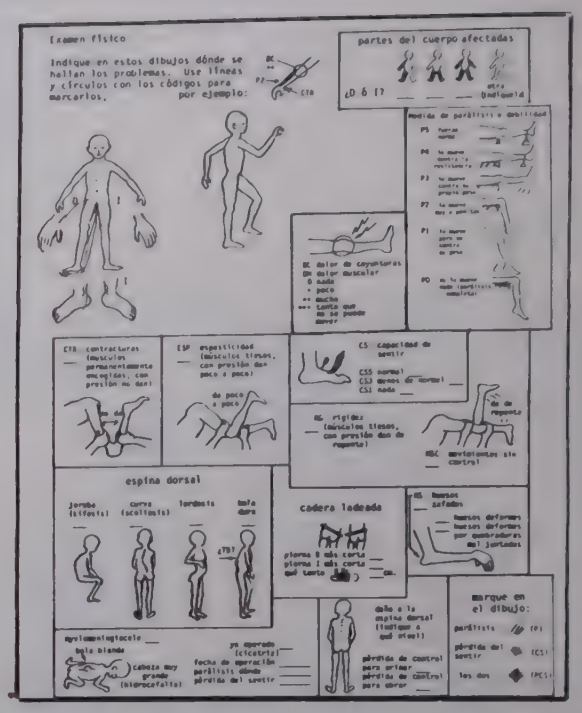
And the man walks away.

Although Salvador has produced these temporary limbs with good results, he is still having difficulty with the permanent limbs. For this and other reasons, production of prosthetics is still not in full swing. But further training is being arranged and we hope soon there will be a good production of low-cost limbs.

Record keeping.

The PROJIMO team feels that record keeping is important--both for follow-up on the children they see and as a basis for self-evaluation and improvement.

But record keeping has not been easy. Only one of the workers has completed secondary school, and some have never attended school at all. An attempt has been made to develop record forms that help guide the workers through history taking, physical examination and management of the problem including advice to parents. But so far it seems the forms are not simple enough and often they are filled out incompletely. Forms are undergoing continued revision as based on suggestions from the workers. Some day we hope they will be adequate.

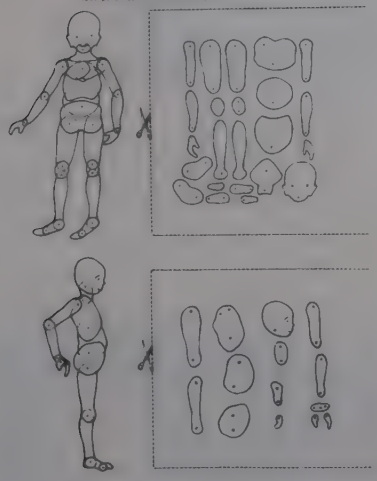

Examen físico
Indique en estos dibujos dónde se hallan los problemas. Use líneas y círculos con los códigos para marcarlos. por ejemplo:
partes del cuerpo afectadas
espina dorsal
cadera ladeada
marque en el dibujo:

The record sheet for physical examination uses many pictures as guidelines and requires a minimum of writing.

'Flexikins'.

One clever idea to simplify measurement and record keeping of contractures and deformities is to use 'flexikins', or jointed cardboard dolls.

Use of the flexikins:



Most of the flexikins used by the program have been cut out and jointed together by disabled children who visit the project.

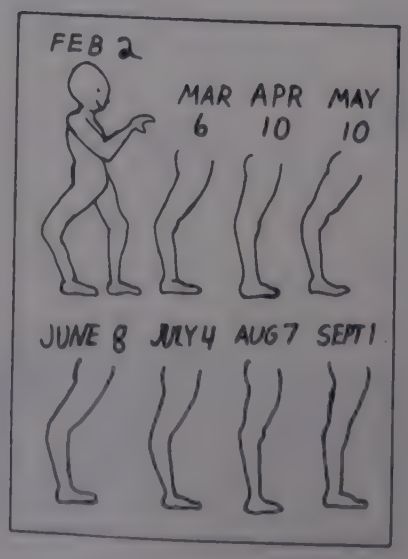
Suppose a child has a doubled back knee like this.

And you want to know if his new brace is helping to correct the deformities.

Hold the flexikin at a distance so that it seems just as big as the child, and angle its leg exactly the same.

Then trace the leg on a piece of paper.

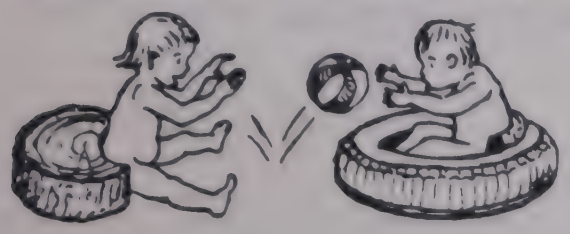
Repeat each month



By using 'flexikins' health workers or parents who cannot read, write, or measure angles can still keep an accurate record to see if and how their child is progressing.

Community education: helping the village accept and appreciate disabled persons.

Helping the disabled child and her family become more able and self-reliant is only part of what is needed for the child to lead a rich or satisfying life. Human beings are basically social; each person needs a friendly give-and-take with the other members of the community. As disabled children grow up, they need to go to school--if possible the same school with ordinary children. They need to relate to other children and adults as equals, as persons--not to be made fun of, not to be over-protected and not pitied as 'poor little things'.



As the disabled children grow up they will need, if possible, to earn a living, to enjoy public entertainment, to establish a loving sexual relationship and perhaps to get married and have children. All this will become easier and more possible for disabled persons as the community becomes better informed and prepared.

People often fear what is different when they do not understand it. Therefore, we must help people in the community to relate to disabled persons as individuals--to get to know them as fellow human beings with strengths and weaknesses, to respect their differences yet preserve what they have in common.

There are several ways in which PROJIMO helps improve the community's understanding and acceptance of the disabled. These include:

- The ongoing activities of the program itself
- Popular theater
- CHILD-to-child activities about disability.

The ongoing activities of the rehabilitation center itself help improve acceptance and appreciation of the disabled through:

- The high degree of community involvement with the program, especially when local families provide room and board for visiting disabled children and their families.
- The training and employment of local disabled youth.
- The playground, or 'Little Park', made by village children, where disabled and able-bodied children play together.
- The fact that the program--in which the community takes increasing pride for its accomplishments and human qualities--is run and largely staffed by disabled persons.

As the disabled workers gain confidence, they have begun to move about the village more freely, sitting in wheelchairs in the town square in the evenings, attending public meetings and festivals and even going to dances.

With so many disabled children arriving in the village (over 270 in the first year) people no longer stare at them as much, or say "Oh, you poor little things!" Instead, they say "Hello, what's your name? Where are you from? How do you like it here in Ajoya?"

And usually the children like it a lot.

CHILD-to-child.

CHILD-to-child is an international program to help school-aged children learn and do more about the health needs of other children--especially their younger brothers and sisters. Activity sheets have been prepared on a variety of basic health topics such as 'Diarrhea', 'Nutrition', 'Accidents', etc. Two activities concerning disability were developed in Ajoya with the help of village health workers, school teachers, and groups in many countries now use the activity sheets they helped to develop.

Children can be either very kind or very cruel to a child who is different. The CHILD-to-child activity "Understanding Disabled Children" helps school children become more sensitive to the feelings, needs, and strengths of disabled children. They do this by taking turns at having different disabilities, then discussing 'what it was like'. Also they act out 'role plays' of different ways a group of children might relate to a disabled child, and discuss why they feel certain ways are better.

Ajoya school children tie a stick to the leg of an able-bodied child, to give him a limp. Then they run races, play tag, and afterwards discuss what the child experienced.

The activity sheet on 'Understanding Children with Special Problems'--as it appears in Helping Health Workers Learn--is included here. (The photographs are from Ajoya.)

The second activity, "Testing for Seeing and Hearing Problems," suggests simple ways that older children can test first- and second-year pupils for weaknesses in hearing or seeing. Even if families cannot afford glasses or hearing aids, it can make a big difference to recognize the child's problem. Then, instead of hiding in the corner, the child can be encouraged to sit up front where she can see and hear better.

Children make their own eye charts to test for vision of young children.

This group of children become the 'instrument' for testing hearing.

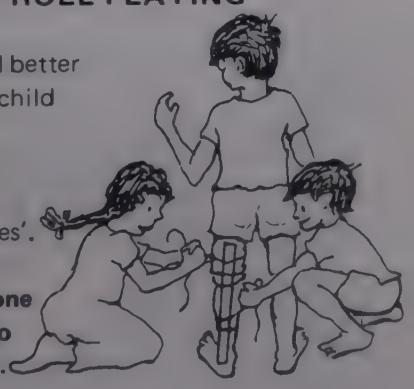
UNDERSTANDING CHILDREN WITH SPECIAL PROBLEMS

GROUP DISCUSSION

Encourage a class or group of children to talk about children who have some special problem or 'handicap'. Ask questions like:

- Do you know any child who cannot walk or run or talk or play like other children?
- Why can't this child do everything the same as you can?
- Is the child to blame?
- How do other children treat this child? Are they kind to him? Are they mean? Do they make fun of him? Do they include him in their games?
- How would you feel if you had a problem similar to this child's? How would you want other children to treat you? Would you like them to laugh at you? To pay no attention to you? To feel sorry for you? To do things with you and become your friend?

GAMES AND ROLE PLAYING



Children will better understand the child with a special problem if they can 'put themselves in his shoes'. They can **play a game in which one child pretends to have a handicap.**

The other children act out different ways of behaving toward the 'handicapped' child. Some are friendly. Some ignore him. Some make fun of him. Some help him. Some include him in their games. Let the children come up with their own ideas and act them out.

After several minutes, another child can pretend to have the handicap. Let several children have a turn with a handicap. Try to make the pretend handicap seem real.

For example, to pretend one child is lame, the others can tie a pole or board to one leg so the child cannot bend it.

Then have the children run a race or play tag. How well does the child with the 'bad leg' do?

After several children have played different handicapped roles, have each of them discuss his experience with the others: what it was like, what he felt, and why.

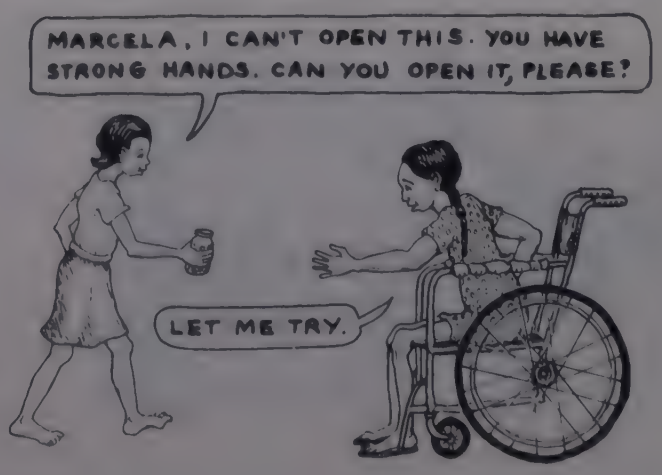
REMEMBER: Children are usually kind to a child with a very severe handicap. They are often more cruel to a child with a less severe problem, such as a limp.

THINGS THAT HANDICAPPED CHILDREN DO WELL

A handicapped child cannot do ***everything*** as well as other children. But often there are ***some things*** she can do as well, or even better. Try to have the children think of examples.

A child with crippled legs, who has to walk with crutches, often develops very strong arms and hands. Or a blind child may develop unusually keen hearing.

Rather than feel sorry for the handicapped child and look only at her weakness, it is better to recognize and encourage her strengths. For example:

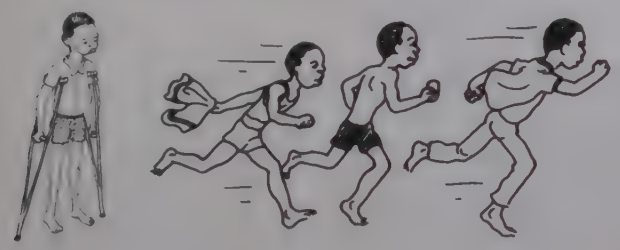


Play with a handicapped child

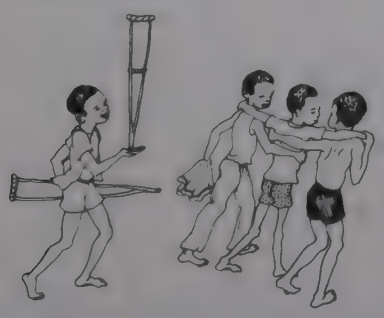
Children, try to include the handicapped child in your games and adventures. Let him do as much for himself as he can, and help him only when he needs it. But remember, he cannot do everything you can. Protect him from danger . . . but do not protect him too much! Too much protection is dangerous to any child's health. Children need adventure for their minds to grow, just as they need food for their bodies to grow.

Swimming

Many children with crippled legs can learn to swim well. Their arms become unusually strong from using crutches, and in the water they easily keep up with other children. But sometimes they have trouble getting to the water, or the other children forget to invite them . . .



A friendly word of welcome to include the child with a special problem, or a little extra time or attention given to him, can make a big difference—and can make everyone feel good.



To help children see how much it matters to the handicapped child to be included in their fun, perhaps they can act out the pictures above.

Photos from Ajoya, Mexico

CHILDREN WITH VERY BAD HANDICAPS

Some children have very bad handicaps. They cannot swim or play many games. But sometimes these children can learn to play marbles, cards, or guessing games.

It is especially difficult for a child who cannot speak or think as easily as other children. This child may be very lonely. Sometimes a child who cannot speak, understands a lot more than people think he does. If there is such a child in your neighborhood, perhaps children could take turns visiting him, to talk or play with him. Let him know you care.

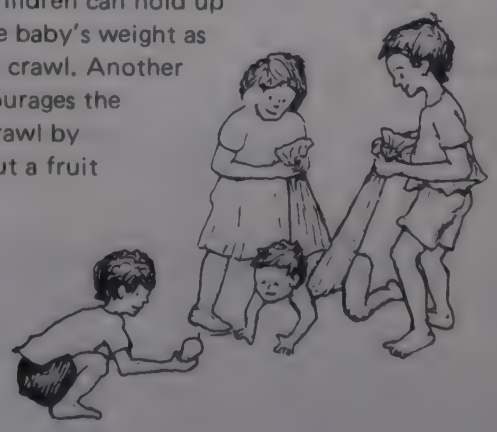
BABIES WITH PROBLEMS

Sometimes a baby has problems that make it very hard for him to learn to sit or crawl or walk. The muscles in his back or legs may be too weak, or may make jerky movements the child cannot control.

A child like this needs special help. Often there are things that older brothers and sisters can do to help the child learn to use both his mind and his body better.

For example: If a child has trouble learning to crawl, perhaps his older brothers and sisters, or other children, can play 'crawling games' with him.

Two children can hold up part of the baby's weight as he tries to crawl. Another child encourages the baby to crawl by holding out a fruit or toy.



Play the game every day. As the baby grows stronger, less of his weight will need to be held up. In time he may be able to crawl without help.

Children in Mexico playing a 'crawling game'.

HOW CHILDREN CAN HELP A HANDICAPPED CHILD

There are many ways that children can help a baby or young child with a special problem to learn to do new things. Here are some ideas:

- **Make it fun!** If exercises can be turned into games, the child will learn faster and everyone will enjoy it more.
- **Self-help.** Help the handicapped child only as much as he needs. Encourage him to do as much as he can for himself and by himself.

A simple bar held by forked sticks can increase the self-reliance of a child who has difficulty squatting to shit.

- **Little by little.** But remember, some things are especially difficult for the handicapped child. Encourage her to do a little more than she already does—and then a little more. If you have her try to do too much, she may get discouraged and stop trying.
- **Show you care.** Show the child how glad you are when she learns to do new things.
- **Mind over body.** Play often with the child, in ways that help her develop not only her body but also her mind. Talk with her and tell her stories. Carry her about. Become her friend.

A rope swing like this can help a child who is lame to help herself learn to walk—in a way that is fun!

Are there any babies or young children in your village who are handicapped or have special problems? Perhaps the other children can take turns playing with these children and helping their families.

Sometimes handicapped children are not given a chance to go to school because their parents are afraid they will find things too difficult. Perhaps a group of school children can visit the child's family. They can offer to take her to school, help in whatever way they can, and be her friend. This could make a big difference in that child's life. CHILD-to-child!

REMEMBER—
ALWAYS BE FRIENDLY!

Popular theater.

In order to increase community involvement in PROJIMO and to help local people understand its activities better, the program uses popular theater. The following two skits were put on soon after the school children had helped build the rehabilitation playground. They tell the story of how PROJIMO began and how the playground was built and is used. The actors are local school-children, disabled workers of PROJIMO, and village health workers from neighboring villages who were in town for a refresher course. The health workers' participation in the skits also gave them experience working with disabled persons and ideas for simple rehabilitation activities and aids in their own villages.

The following pictures of the skits are available from the Hesperian Foundation as a slide show.

The Farmworkers' Theater presents

"HELPING YOUR NEIGHBOR"

--the story of how Project PROJIMO got started and how village school children built a playground for disabled and able-bodied children.

A disabled young man (played by Marcelo) arrives at Ajoya and asks directions to the village health center (Project Piaxtla).

The health workers examine him, find he is disabled by polio and suspect he may need braces. But they lack the knowledge about what to do for him, and so send him away unattended.

The health workers are concerned: "So many disabled children come to us. Most don't need hospitalization or surgery, but simpler things like braces or special exercises. Yet we don't have the knowledge or skills to provide these. Why don't we try to get more training and start a rehabilitation program for disabled children? We can focus on what parents can do for their children in the home."

The health workers meet with villagers to discuss the new program. Villagers respond enthusiastically. Men offer to help fix up the center. Women offer to provide room and board for visiting children and their families. And the school children offer to help build a rehabilitation playground--on condition that they can play there too.

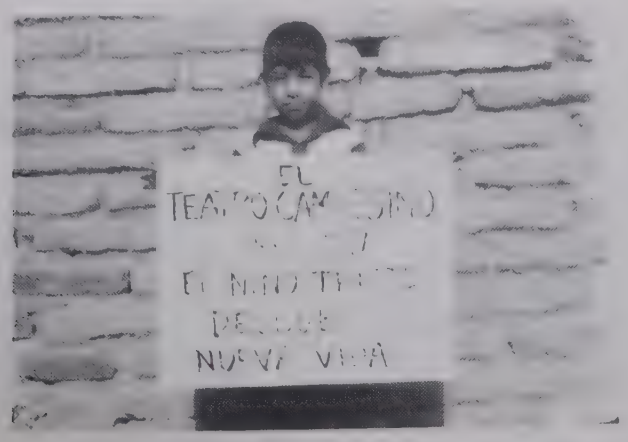
The school children--who had already built the actual playground in the village--quickly rebuilt the playground on stage.

Having already dug the holes for the poles, with practice they were able to assemble the playground on stage in about 3 minutes.

In this way villagers had a chance to see how different equipment in the playground is used--like this 'rocker board' to help children with balance problems, and the sitting frame to help a spastic child keep his legs spread while he plays with homemade educational toys.

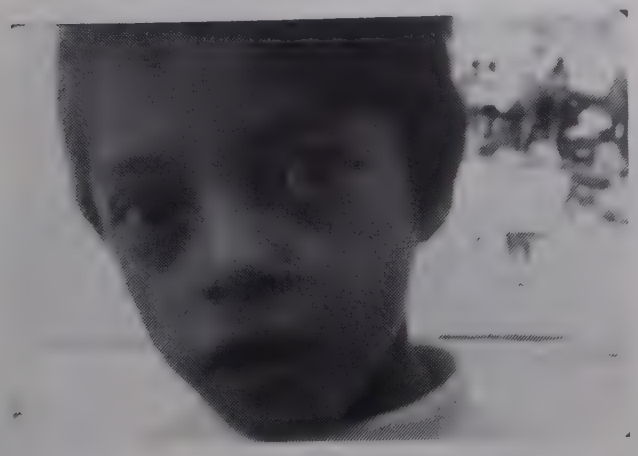
COMMUNITY HEALTH
LIBRARY
WC100

The second skit is a continuation of the first.



The Farmworkers' Theater presents

A SAD CHILD
DISCOVERS NEW LIFE

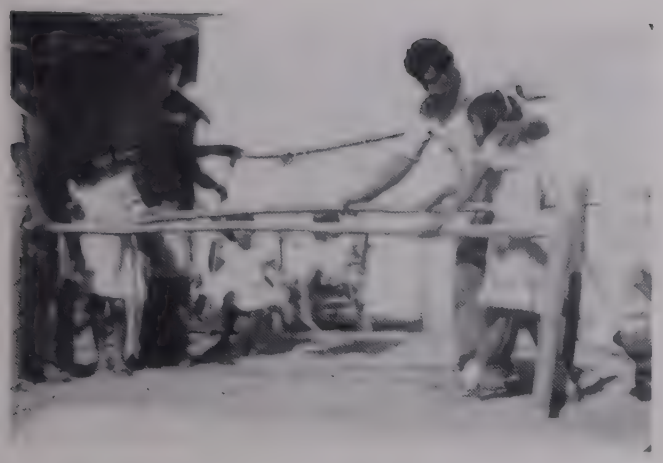


This is the sad child, Tristin.

His role is played by Inez--one of the disabled village workers. In fact, the skit comes close to telling Inez's own story. Like Tristin in the skit, Inez is an orphan disabled by polio who was helped by PROJIMO to get braces, and then stayed on as a rehabilitation worker.

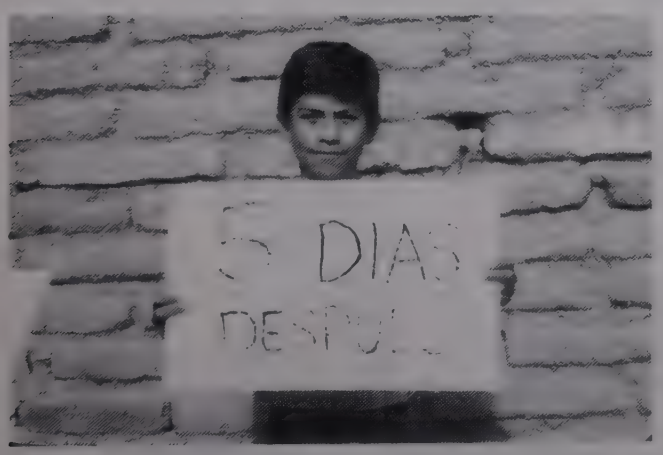
Marcelo, a village rehabilitation worker, finds Tristin in a home. The boy is unhappy because he cannot walk and has no friends. Marcelo invites Tristin to come with him to PROJIMO.

They arrive at PROJIMO, and Marcelo shows Tristin around the playground

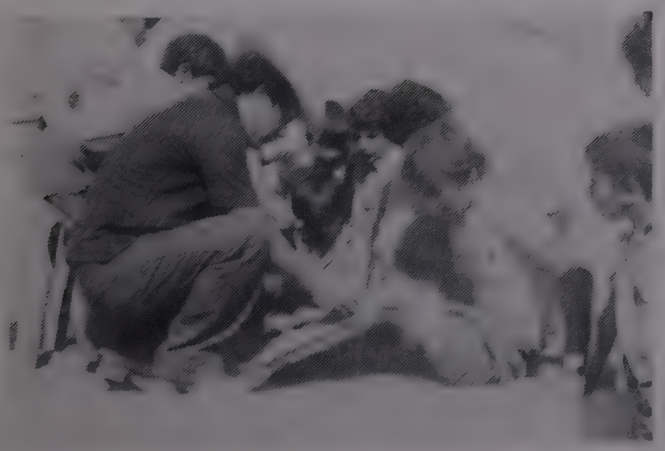


Tristin (and the audience) have a chance to see how the playground equipment is used to help disabled children learn to walk and do other things.

They see how the sitting frame and homemade games are used; also how a child who cannot sit lies on a sloping platform so he can lift his head and use his hands.



5 days later



The village rehabilitation workers have made a brace for Tristin, and here fit it onto his leg.

Then they help him learn to walk with the brace, using the parallel bars.

Tristin learns quickly and soon begins to walk with crutches.

The time comes that PROJIMO has done what it can for Tristin in terms of physical rehabilitation. "Where do you go from here?" they ask him. "I don't know," he answers. "I have no family to go to. I've never gone to school. Work is hard to get even for the physically fit." "Why don't you stay with us and help in the rehab program? You can learn some skills and help other children like yourself."

Tristin decides to stay, and begins to learn rehabilitation skills. Here a mother arrives with the first child whom Tristin attends as a 'rehabilitation helper'.

Together the team examines the child, who appears to have cerebral palsy affecting mainly his legs. The team believes he has a good chance of learning to walk.

Tristin shows the child's mother how she can help him learn to walk using the parallel bars.

At last the little boy learns to walk. But just as important, he has new hope, new friends and new self-confidence. He sees other disabled persons like himself who are not only leading full lives, but who are working hard to serve others in need. As the skit ends, Tristin lifts his young friend onto his shoulders and raises his crutches in a sign of victory.

The ending of this skit was even more impressive for the village audience because they had seen Inez (who acted Tristin) when he first came to Ajoya. They knew that his transformation from a severely handicapped, withdrawn youth to a fast moving, capable, young man was not just acted--it was real.

And because PROJIMO is the village's program, everyone felt proud.

Outreach, contrasts with other programs and referral.

In Mexico PROJIMO has established relationships with an increasing number of programs working with the disabled:

• Arrangements have been made for free (or almost free) orthopedic surgery in selected cases at the Hospital Civil in Culiacan (the state capital).

• A team of women community leaders from the DIF (Integrated Family Development) program in Culiacan has visited PROJIMO and is eager to cooperate in whatever way they can.

• The CREE simplified rehabilitation program in Toluca, which helped train 5 PROJIMO workers in November, has offered further training and individual apprenticeships for PROJIMO workers.

• A very close relationship has evolved between PROJIMO and an organization of families of disabled children known as 'Los Pargos', in the city of Mazatlan. So far Los Pargos has transported over 30 children to the PROJIMO center in Ajoya for therapeutic counseling, orthopedic aids and braces, wheelchair repair and other services. Also 7 of the Pargos children have been taken to Shriners Hospital for difficult orthopedic surgery such as spinal fusion.

• PROJIMO rehabilitation workers have visited the Pargos school and 2 of the Pargos teachers (themselves disabled) visit PROJIMO regularly for 'inspiration' and to get ideas about group therapy in school.

One of the suggestions for the classroom is that rather than having the children always study in their wheelchairs, they spend part of their time lying on their bellies.

Sitting like this all day long causes back problems and contractures of the hips and knees--a problem many of the Pargos children have been developing.

Lying like this for several hours a day (while studying or being read to) helps prevent back problems and contractures.

The Pargos children have, in turn, donated many of their splendid paintings and sea life art work to decorate the walls of the PROJIMO center.

With the help of the leaders of Los Pargos, PROJIMO is trying to start similar organizations of families of disabled children in other towns and communities. In one large village, Piaxtla de Abajo, the first steps toward such an organization are being taken with families who have visited PROJIMO.

In California, through the Hesperian Foundation (the support organization for Piaxtla and PROJIMO), cooperative relationships have been set up with several organizations. The following have served as referral bases for children requiring highly specialized care:

• Shriners Hospital in San Francisco continues to provide completely free hospitalization, surgery, and specialized care to children from Mexico.

As many as 11 disabled children at a time are transported 1600 miles from Ajoya to Shriners Hospital--and back again. Volunteers are recruited to help drive.

The PROJIMO team is trying to make arrangements for orthopedic surgery in the nearest cities, but costs are very high. However one orthopedist in the state capital has now begun to provide free surgery for selected persons referred by PROJIMO.

This child whose hip became frozen from an infection in early childhood, was referred by PROJIMO to Shriners for surgery. He now walks straighter.

• The Plastic and Reconstructive Surgery Department at Stanford Medical Center in collaboration with Interplast (International Plastic Surgery Program) provides free surgery for children with harelips, cleft palates, burn deformities, etc. Interplast operates on some children in Navajoa, Mexico. The Interplast program actually began when surgeons from Stanford began doing volunteer surgery in Mexico for Project Piaxtla.

• St. Mary's Hospital in San Francisco has also helped children with disabilities that Shriners Hospital does not treat.

• In the San Francisco Bay Area, a network of volunteer 'foster families' cares for the children in the U.S.A. when they are not in the hospital.

Training village workers, and review of written materials.

Groups in California that have helped teach the PROJIMO trainees include the Physical Therapy Department at Stanford Medical School and at Stanford Hospital, Rehabilitation Engineering at Stanford Children's Hospital, Orthotics Design in Redwood City, Shriners Hospital in San Francisco, Hittenberger's Prosthetic and Orthotic Services in San Francisco, Valley Hospital Physiotherapy, Center for Independent Living, Berkeley, and Ralf Hotchkiss Wheelchair Design in Oakland.

Internationally various persons and organizations have also been collaborating with PROJIMO. Many have received and are trying out draft sections of the new rural rehabilitation manual. Included are UNICEF, Rehabilitation International, Peace Corps, Partners of the Americas, Mobility International (all U.S. based); Institute of Child Health (London); CHILD-to-child (London); Sophie Levitt, author of Cerebral Palsy and Motor Delay (London); AHRTAG, (London); Center for Rehabilitation of the Paralyzed (Bangladesh); Jaipur Orthopedic Center (India).

Financing. The long-term goal of PROJIMO is to become as economically self-sufficient as possible, while at the same time continuing to provide services and orthopedic equipment at a price poor families can afford. The (admittedly idealistic) plan to achieve this calls for:

• A dedicated non-professional (no degrees) staff who are willing to work at wages close to those of ordinary laborers and farmworkers, a staff who pride themselves in serving poor families at low cost.

• An enthusiastic community that gives a lot of volunteer assistance, provides room and board for PROJIMO workers at a price that barely covers the cost of food.

• Technology that is 'appropriate' in that it uses whatever resources are free or cheap, easily (if not always locally) available, and which serve the purpose. For example, workers usually make metal braces by taking apart and rebuilding old donated braces. Such technology is labor-intensive in that it demands extra work (taking old equipment apart and rebuilding it) but provides poor families with high-quality equipment at the modest cost of labor.

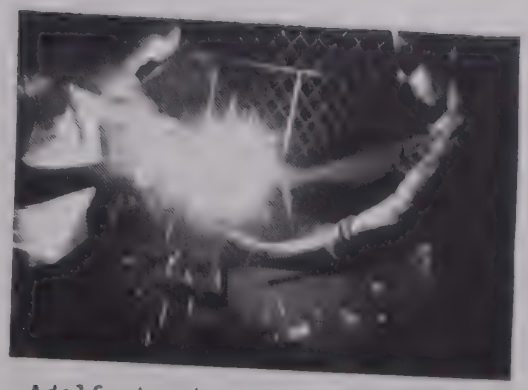
The metal joints on these braces were taken from old braces that were donated to PROJIMO.

• Modest fees for services and 'at cost' charges for equipment--with an understanding that charges can be reduced if the family has great difficulty paying.

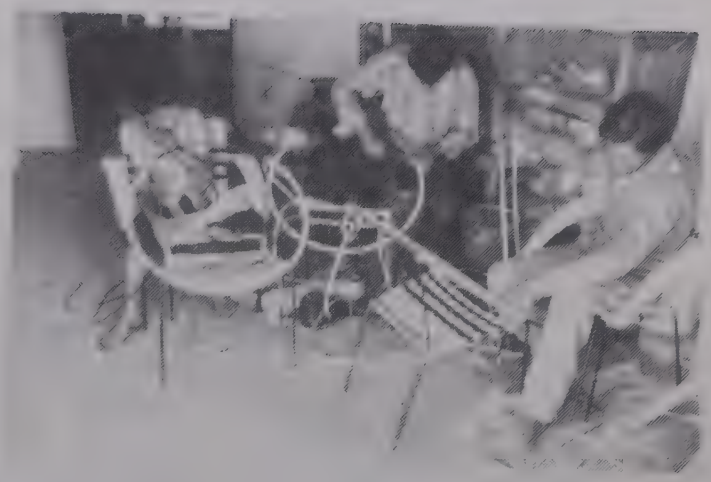
• Income producing activities that provide skills training for disabled workers as well as bring in money through the sale of goods. So far the 'goods' produced for this purpose have been sandals, and metal frame, plastic woven chairs. The sandals and chairs are sold locally at low cost. So far the demand has been much greater than the production.

Sandals for sale by PROJIMO, made from leather with car tire soles.

So far it is doubtful that the production of chairs and sandals has really produced any income for the program. The workers are still learning the skills. While some work fairly fast, others are slowed down by their disabilities or their lack of 'work habits', and so far do not produce enough to cover their living expenses. But little by little, production is improving.



Adolfo teaches Marcelo to weld reinforcing rod to form a chair frame.



Weaving the chairs--village children also come and help.

'Occupational therapy'. A child with cerebral palsy helps paint a chair frame.

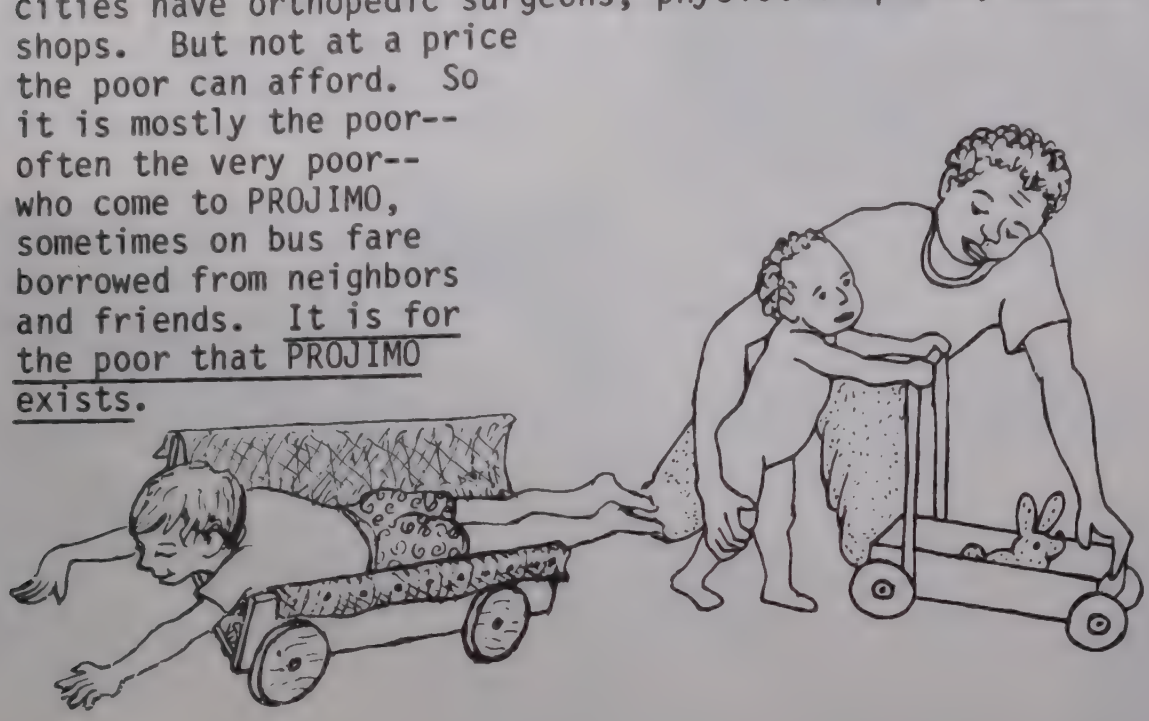
Javier teaches younger children to make baskets from the leftover bits of plastic and old beer cans.

Eventually the team hopes that other items such as wheelchairs and educational toys can be sold at a modest profit, even though prices will be lower, and quality (they hope) higher than what is commercially available.

PROJIMO's goal has been to become more or less self-sufficient within 3 years. Realistically, this may not be possible, especially if the project continues to serve primarily those families whose needs are greatest.

The biggest obstacle to economic self-sufficiency of any community project is poverty. A family that does not earn enough to feed its children adequately, cannot pay even modest costs of health services--at least not without increasing the health risk for its children. And because of the high risk, the demand for services is high. Consider a team of low-paid, dedicated workers who are flooded with demand for their low-cost, friendly services. Is it fair that such a team must also produce 'income generating goods' in a struggle for self-sufficiency? Ideal as it is not to depend on 'outside funding', true self-sufficiency of a community service program may only be possible through the process of major social change. Only when enough jobs are available, and nearly every family earns enough to meet their basic needs, can we honestly think in terms of program 'self-sufficiency'.

PROJIMO has come face-to-face with this problem. Ironically, over half the disabled children who come to the village rehabilitation center come from the slums of the cities! Families make costly, time-consuming journeys of 80 to 120 miles to a remote village to seek help for their children. Why? The cities have orthopedic surgeons, physiotherapists, modern brace and prosthetic shops. But not at a price the poor can afford. So it is mostly the poor--often the very poor--who come to PROJIMO, sometimes on bus fare borrowed from neighbors and friends. It is for the poor that PROJIMO exists.



So even though PROJIMO produces walkers, special chairs and orthopedic braces at from 5 to 20% of the commercial prices, many families still can only pay a fraction of the costs. If a child and mother need to stay for 2 or 3 days for therapy, training, or to have braces made, sometimes PROJIMO has to contribute the cost of food. Some families have chosen to sleep on the floor of the rehabilitation center rather than to pay 50 pesos (US$0.30) to rent a cot.

People's poverty is real, and the expenses involved in trying to meet the needs of a disabled child can be considerable, even if everything is done at the lowest possible cost. Until a more just society exists (and perhaps for certain families, even then), some kind of a subsidy is needed if the disabled children in greatest need are to be adequately attended.

To provide such a 'subsidy' and still give the rehabilitation workers the sense that they are earning their keep, a special 'auxiliary fund' has been set up. (Sources of outside funding will be discussed in a moment.) The 'auxiliary fund', which is kept in a separate bank account, pays the PROJIMO team the difference between what a poor family pays and the actual cost of producing a therapy aid or orthopedic equipment. In this way the work of the team does in fact 'bring in money' and the team can have a better sense of its accomplishments and efficiency.

At present, although enthusiasm is high and the team often ends up working 7 days a week, efficiency is low. However, it is steadily improving. The village team finds it has to develop organizational and management skills along with everything else. At times it is frustrating, but usually it is exciting. Above all, the team has the sense that they are running their own program, and the challenge is as great as the responsibility. The group has defined their leaders as coordinators--not bosses--and are quick to react if the coordinator tries to boss. This struggle for truly democratic leadership (a rare thing in Latin America--or anywhere) probably also decreases efficiency, but makes the process more exciting. It is the team's first small step toward a fairer society--which must be the ultimate goal if they and those they serve are ever truly to become self-sufficient.

How the team pays itself.

The PROJIMO team has discussed repeatedly and at length the question of salaries. Most of the workers agree that, to make their services more affordable to the poor, their salaries should be modest: enough to cover their basic needs, and not much more. They would choose to have the limited amount of money available for salaries spread among more workers.

Unfortunately, not every one feels the same. The two able-bodied craftsmen who were sent to other countries to learn (and then teach) particular skills have demanded 3 to 4 times the salaries of the other workers. The team has agreed to pay what they demand only because, for the present, these two persons are irreplaceable. And it appears they would like to remain irreplaceable, for they have been slow to teach their skills to others. Needless to say, this has caused some hard feelings and angry discussions.

What can be learned from this? The team feels that they made a mistake in choosing skilled, able-bodied craftsmen to get the special training. They thought (quite rightly) that having related skills already, the craftsmen could learn the new skills more quickly. Now, however, the team feels that the first consideration should be a worker's commitment to the cause and to the group. It would be wiser to send a lesser skilled person who would be eager to share his knowledge and work as an equal to the rest. The team agrees that it should get new people trained to replace the craftsmen as soon as possible.

The team has tried to work out a fair plan for salaries. Some persons obviously work much harder--and longer hours--than others. Some of the more disabled persons clearly could not produce as quickly as others. But the group decided that it is how hard and long a person works that matters most--not how much he or she produces. So they decided to keep track of the hours that each person works and figure out pay accordingly. Some of the younger workers and new arrivals have never worked seriously before, and have often--because of their disabilities--been spoiled or over-protected. These persons often have started off playing or fooling around more than they have worked. The team decided to provide room and board for such persons with only a little 'pocket money'--and a promise of better wages when they really settle into work.

Wages at present range from 4000.00 pesos (US$27.00) per month (for those who are still not very serious about their work) to 8000.00 pesos (US$55.00) for the hardest workers, and 20,000 and 25,000 pesos for the two craftsmen. Wages, although low, are similar to what other working people in the village area earn.

Funding.

PROJIMO has a 3-year grant from The Thrasher Fund (Utah, U.S.A.) which provides approximately $15,000.00 per year. This is the 'launching' money for the project, with the hopes that at the end of 3 years it will become more or less self-sufficient.

Additional funding for the 'auxiliary fund', building projects (such as the new therapy/consultation room and the water therapy pool), preparation of the Rural Rehabilitation Manual, and the prolonged rehabilitation of specific children, have been provided by the Mulago Foundation, the Packard Foundation, Liliane Fonds, and private donors. Salvador's trip to Thailand and Ralf Hotchkiss' trip to Ajoya were paid for by Appropriate Technology International. Brot fuer die Welt provided funds for the development of teaching materials. Medical costs of children taken to Shriners Hospital, Interplast, etc., are covered by the respective institutions.

Evaluation.

At first, the major funding agency (Thrasher Foundation) wanted an outside, highly qualified evaluation of PROJIMO. However, the team felt strongly that 'participatory evaluation' carried out by the rehabilitation workers themselves with the help of the local community and families of the disabled children would be more meaningful--at least to them.

And so it has been. Admittedly the written monthly evaluations leave much to be desired. But the process of gathering information systematically, trying to keep careful records, periodically analyzing accomplishments, problems and possibilities for improvement, has been an extremely valuable experience for those involved.

David Werner helped the team with its self-evaluation by drawing up a series of forms and guidelines (admittedly very imperfect--they are being reworked, based on suggestions by the team). In addition, questionnaires have been sent out to families of the disabled children, one month or more after they were first attended by PROJIMO.

Visiting therapists and other specialists also help the group to evaluate their work, and sometimes write lists of suggestions.

Accomplishments.

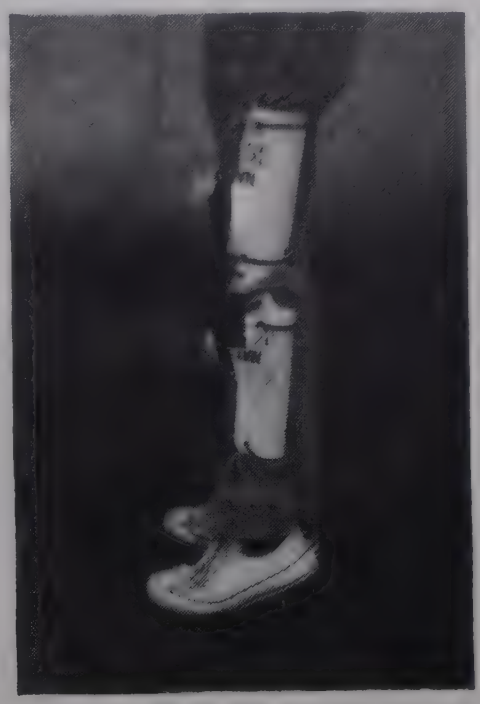
Overall, it can be said that in PROJIMO's first unofficial year (September 1982 to August 1983) much was accomplished: 274 disabled persons were attended, over 200 of them children. Of these the village team was able to attend with recommendations, therapy and/or orthopedic equipment about 90%. Hospital care and/or surgery was arranged for 24 children and 2 adults.

Over half of the children seen by PROJIMO workers were reviewed at one time or another by visiting therapists. This not only meant more and better services for the children, but a marvelous learning opportunity for the rehabilitation workers (and families of the children). By the spring of 1983 the workers were beginning to gain more confidence in diagnosing problems, and making decisions about recommendations, therapy, and choice of aids or orthotics. However, everyone still has a lot to learn.

The PROJIMO team is strong in 'technology' (making things and applying therapy). Several workers have become remarkably skillful--even creative--at making braces, special seating, walkers, and therapeutic aids. They have also become skillful at straightening out contractures and correcting club feet. They have fairly consistently had good results.

Sometimes the team has become quite creative in designing and building orthopedic or therapeutic aids. Here is one example.

Many children with polio in one leg hold their leg like this when they walk because the thigh muscles are weak.



For this young man, the PROJIMO workers designed a 'thigh-muscles-assist' using plastic bucket and inner tube.

After experimenting with the plastic bucket model, they made a polypropylene brace with the same design.

This let the young man walk bending his knee but without needing to use his hand.

The PROJIMO team reports that in their first year they have had clearly beneficial physical results in 60% of the children attended. Of the remaining 40% of children and their families, many also benefited, but in ways more difficult to assess--such as emotionally or with a new sense of hope. Or sometimes, by helping the family learn to accept a child's disability and making the most of her remaining strengths, rather than continuing to hunt for a 'cure'.

Obvious improvements have most frequently been observed or reported in these areas: 'gait' (how the child walks), 'posture' (correction of deformity-causing positions when sitting or standing), angle of contractures, and range of motion. Also, at least 8 children who were unable to walk are now walking (some with the help of braces, crutches, or walkers). 12 are able to get from place to place better on rolling boards, scooters, or wheelchairs. 7 children who lacked body control for sitting are now doing so thanks to a combination of therapy and special seating.

Sometimes improvements are immediately visible. This child was developing a spine deforming curve of the back because of a short leg (polio). When the sole of his sandal was thickened, he at once stood straighter. This is 'preventive' orthotics because it helps prevent back problems later.

8 year-old Edgar is paraplegic. Orthotists had prescribed braces, which he could not use. With this simple walking frame made by PROJIMO, he began 'swing through' walking on parallel bars.

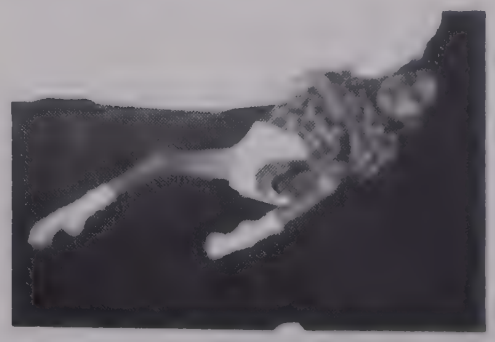
Miguelito, who is spastic, was unable to walk independently when he first came to PROJIMO.

He and his grandmother and sister stayed with PROJIMO for two weeks total (over a 3 month period). Miguelito advanced from parallel bars to crutches to unaided (though still awkward) walking. The biggest job was to get the family not to help him too much when he tried to walk.

Soon Edgar advanced to one bar and a crutch. Here he races Miguelito, who is learning to walk with crutches.

In terms of skills for self-care, many children have benefited, in different ways, including dressing, self-feeding, and use of the toilet.

Two severely disabled children, age 6 and 8, one with polio and the other with arthrogryposis, will probably never walk. Here they play together rolling on the floor. Neither child was toilet trained when they came to PROJIMO. Both learned within a week.



Gabriel cannot raise his hands to his face because he lacks the necessary arm muscles. He depended on his mother giving him every mouthful of food.

Here Gabriel is learning to lift food to his mouth using his neck and back muscles to raise and lower his arm that is balanced on the table. He delights in his new sense of independence.

How many children and their families have benefited socially and psychologically from their relationship with PROJIMO is hard to say. Most parents' responses on questionnaires have been very favorable. Also it is significant that so many families keep coming back--especially those whose children have very severe problems where little can be done physically. As one father expressed it, "Coming here to PROJIMO refreshes the soul."

Developmental delay and mental retardation are areas in which the team had not planned to get involved at first. However, many of the multiply handicapped children are also retarded--especially those with cerebral palsy or epilepsy. Therefore, the team has had to learn some basics of developmental stimulation. Ironically, this has become one of the areas where parents have been most grateful for the clear advice and instructions the team provides. However, the team still feels the need to learn a great deal more. The visiting therapists have been a great help in teaching them in this field.

8 year-old Jesus, with athetoid cerebral palsy, comes from a difficult home situation. His father is a drunkard. Jesus cannot walk and has very poor balance. He had mostly been kept in a dark room. He became deaf because of frequent untreated ear infections. Developmentally he was far behind. He was not toilet trained and could communicate almost nothing. In the six weeks that Jesus was with PROJIMO, he became toilet trained, learned to express himself through a few gestures and signs, began to play with other children, and even helped build therapy aids. He truly blossomed.

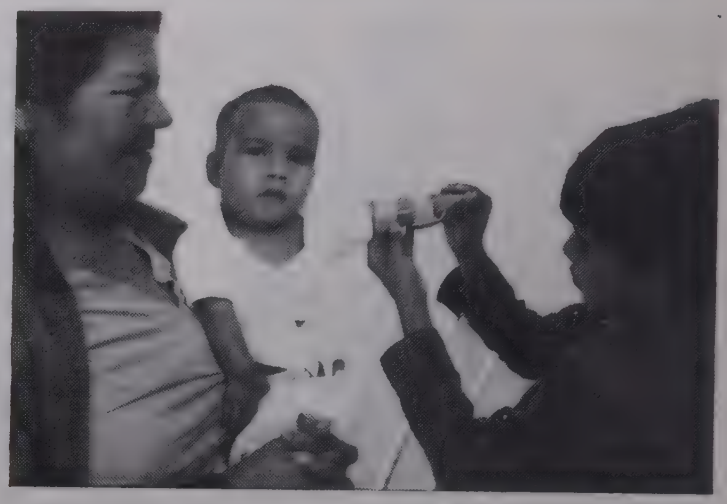
Here Conchita helps him to exercise both body and mind--stretching and balancing on his knees to place blocks in the right-sized holes. The learning game is made from a cardboard box with different shaped pieces of wood.

The team is still trying to find ways to help improve Jesus's family situation. Two of the PROJIMO workers (who themselves have had drinking problems) have started a sort of 'Alcoholics Anonymous' locally. But they have still not reached Jesus's father.

Comparing the village team's work with that of professionals in nearby cities.

When a team of village workers tries to provide services normally carried out by highly trained professionals, the questions naturally arise: "Is their work adequate? Is it 'cost effective'? Does it not increase risk to clients? How does their work compare with that of more fully-trained, degreed, and learned professionals? In the opinion of visiting therapists--who are often outstanding in their field--much of the work of the village rehabilitation workers compares fairly well to that of therapists, orthotists, (brace and prosthetics makers) and orthopedists in the neighboring cities.

For example, on several occasions the village rehabilitation workers have succeeded in correcting contractures or club feet that orthopedists had tried and failed to correct. On another occasion a boy had such a tightly contracted foot that visiting therapists recommended surgical correction. The team decided to try casting 'just in case'. The results were so good that when the boy was seen by an orthopedic surgeon, he congratulated the team and said that surgery was no longer necessary. On several occasions the PROJIMO workers have replaced heavy uncomfortable metal braces, which the children refused to wear, with lightweight plastic braces which the children ended up wearing.



This boy was born with club feet and a clubbed hand. An orthopedist had tried to correct the feet by casting but had given up and recommended surgery after large sores formed under the casts. The village rehabilitation workers successfully corrected the clubbing. Here a village boy has made a plastic bucket splint for the hand.

Time and again children are brought to PROJIMO with heavy, awkward hip-high braces, when single below-the-knee braces would meet their needs better--or at times, no brace at all. Children with minor back problems have been put into elaborate 'straight jackets' when leading normal, active lives would do them far more good. The tragedy is that poor families can often spend a fortune for this useless, uncomfortable, unsightly equipment. Why? Perhaps because the orthotists think they need such equipment. Or perhaps because they want to make a lot of money.

In any case, the PROJIMO team, which provides braces and equipment at or under cost, does not have the temptation to overprescribe.

A big problem in Third World countries for those who do receive orthopedic services is 'overkill'. This girl was prescribed these expensive, heavy, high braces by an orthopedic surgeon. The girl hated them and PROJIMO workers found she walked much better without them. °Visiting therapists agreed she should simply not use them. She was delighted.

Visiting therapists have often commented on the low cost, the appropriateness, and the quality of orthopedic aids built by the PROJIMO team--as well as how quickly they have them ready (often the same day the first measurements are taken, although on busy days this often means working extra hours).

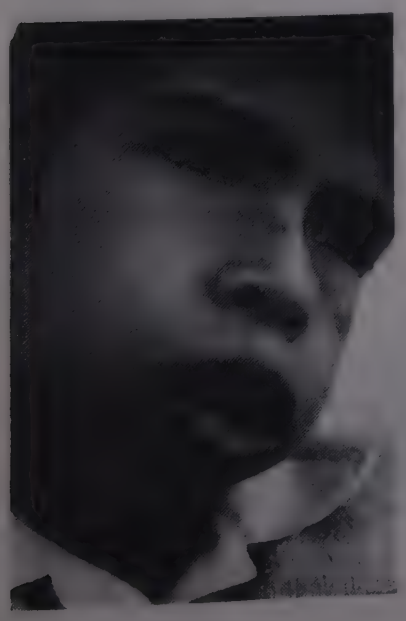
So far, complications from the PROJIMO workers' orthopedic procedures have been relatively few. For example, of 23 children put into casts, only 2 developed minor pressure sores. From what we have seen of similar casting in hospital wards, this compares well.

Moreover, there appears to be no major damage caused by any of the village rehabilitation workers. As far as we know, only 2 children have had any increased difficulty as a result of attention provided. One had increased discomfort walking after PROJIMO workers straightened a contracture. The other had more difficulty walking after minor corrective surgery at the orthopedic hospital to which he was referred.

There are different ways of looking at 'cost effectiveness'. The village rehabilitation workers often take more time with individual children and their families and more hours to produce a brace or special chair than would experienced professionals. They also do more 'wasting time' and 'fooling around'. However, the end product is often of good quality at very low cost (from 2% to 20% of the cost of professional or commercial products). When you consider that disabled workers are not only gaining confidence and skills as they work, but also give confidence and hope to the disabled children and parents who watch and help, the value of such a 'non-professional' approach becomes immeasurable.

Even medically the work of the village rehabilitation workers (some of whom first worked for years as village health workers) sometimes compares favorably with professional care provided certain children. Here are 3 examples:

This little boy with epilepsy was kept on Dilantin (diphenol hydantoin) by his doctor for many years. The result was this tumor-like growth of the gums. The rehabilitation workers changed him to a cheaper medication and now his teeth are reappearing as the gums shrink. He also has fewer fits.



Hector has Potts' disease, or tuberculosis of the spine. The PROJIMO team diagnosed it by how it looked, how it began (bit by bit) and by the fact that Hector's father has tuberculosis. For treatment of TB, they sent Hector to 3 different centers, including the national tuberculosis control center in Mazatlan. All 3 medical centers claimed Hector's back deformity was not caused by tuberculosis. They said it was from a 'traumatic injury' (even though it had begun slowly without pain). Finally PROJIMO sent Hector to Shriners Hospital in San Francisco where surgeons removed a quart of pus from tuberculosis abscesses of the back muscles, and fused the 4 vertebrae (back bones) that had been destroyed by tuberculosis.

Joaquin, now 13, was hit by a truck at age 5. The flesh was torn from his right thigh. The driver bribed the authorities not to hold him responsible, so Joaquin's mother had no financial help. Joaquin was treated in the Children's Hospital in the state capital. Intravenous solution was administered in the good leg, but due to carelessness the liquid all ran into the muscles, not the vein. So the good leg became infected and had to be amputated. Joaquin was released from the hospital with a huge open infected area in the right thigh. The infection continued for 7 years (until he came to PROJIMO) and "at times he would lose weight because it smelled so bad he couldn't eat." His mother had saved her money and had taken him to a private doctor, who had treated him for 5 months with costly antibiotics. But the same infection had continued. At PROJIMO the team thought that by now the infection was probably antibiotic resistant. So they tried treating it primarily with soap and water. In 3 days the 7 year-long infection was under control and in 2 weeks the open sore had healed to half its size!

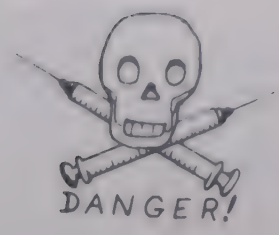
While Joaquin was in PROJIMO undergoing treatment, the team invited him to help in various ways. Here he helps Roberto build a special seat for another disabled child.

PROJIMO arranged for surgery to straighten Joaquin's hip and knee. Now he is walking with the help of an artificial leg.

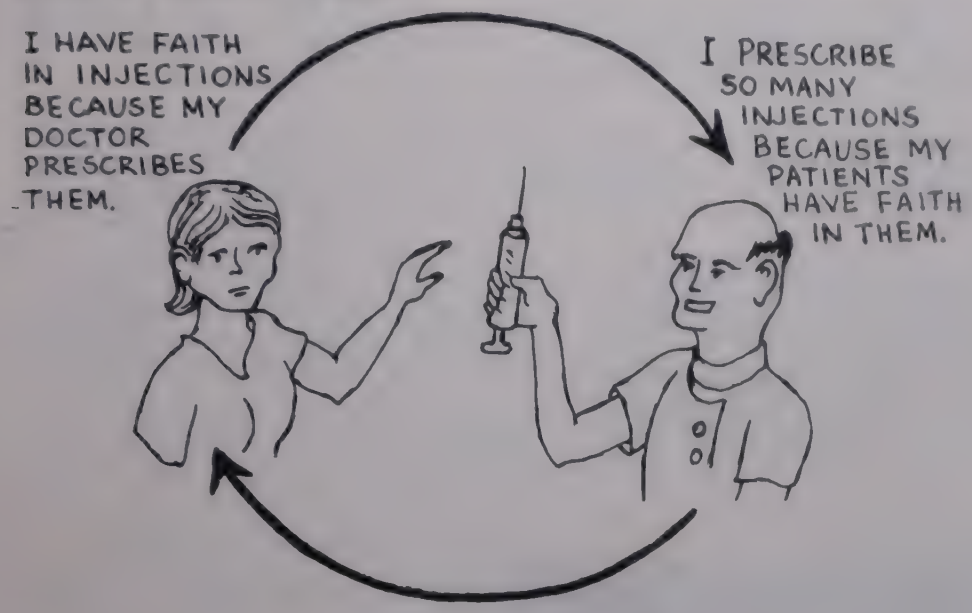
And here he helps make 'flexikins'.

Preventive measures:

PROJIMO's campaign against overuse of injections.



In most developing countries, injections have become the 'modern magic'. People demand them because doctors and health workers so often prescribe them, and doctors and health workers prescribe them mostly because the people demand them.


I HAVE FAITH IN INJECTIONS BECAUSE MY DOCTOR PRESCRIBES THEM.
I PRESCRIBE SO MANY INJECTIONS BECAUSE MY PATIENTS HAVE FAITH IN THEM.

A VICIOUS CYCLE:
OVERUSE AND MISUSE OF MEDICINES

The result is that injections are often given when medicine could be more safely given by mouth if any medicine at all is needed.

Many problems result from the overuse of injections, especially in areas where doctors are few and people, following the example of the doctors, overprescribe injections for themselves.

Because care in keeping syringes and needles clean is often lacking, abscesses resulting from injections are common. Sometimes they become very severe. Here is one example.

Jésica was injected at 3 days of age (her mother does not know why). An infection resulted that reached her spine, permanently paralyzing her legs.

Her feet became clubbed and when she tried to stand on them she developed a huge pressure sore (because her feet lack feeling).

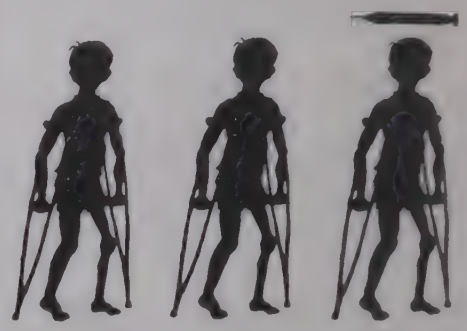
Javier cast her feet to begin to straighten them and to protect the sore. Around the sore he left a window in the cast, to allow cleaning.

Infections and abscesses are not the only complication from injection. There is evidence from various parts of the world that link paralysis from polio to injections. Most children who become infected with the polio virus develop signs of a bad cold, but do not become paralyzed. If, however, the child is given an injection of any medication the injection can 'trigger' the virus infection to cause paralysis.

PROJIMO has begun its own study of the relationship of polio to injection. Its data so far shows that:

83% (25 out of 30) of children with polio seen by PROJIMO had received an injection within 2 weeks before they were disabled by polio.

83% (10 out of 12) of the parents who could remember in which buttock their children had been injected, reported that the injection had been given on the side of the body that had become most paralyzed.



Today 1 of every 3 cases of crippling polio is caused by injections given to children. These children already have mild, undiagnosed polio, which is often mistaken for a severe cold. The injected medicine irritates the surrounding muscles, and can cause paralysis in the arm or leg.

A village health worker takes vaccines on ice to distant mountain villages.

In view of the frequent complications caused by injections--widespread abscesses, spinal cord injury, and polio--both Project Piaxtla and PROJIMO have a campaign to educate people about the risks of unnecessary injections. This preventive campaign includes posters, popular theater and frequent personal warnings. Once the families of children with polio learn that their child's paralysis may have resulted from an injection, those families also become convincing campaigners against overuse of injections.

PROJIMO also encourages parents to vaccinate their children against polio, measles, and other infectious diseases of childhood that can lead to death or disability.

For years, village health workers in PROJIMO's sister project, Piaxtla, have conducted a vaccination program in the surrounding mountain area. It has been so effective that in the last 16 years, in their area of coverage, only 1 case of paralytic polio has been reported. By contrast, outside the area of coverage--including the cities--polio remains the biggest cause of childhood disability.

PROJIMO FACT SHEET
SEPTEMBER 1982 to SEPTEMBER 1983
(Some of the numbers are approximate)

- 16 staff members: 11 disabled, 5 able-bodied.

- Number of disabled persons attended: 274; 210 of them children, 124 boys and 86 girls.

- 47 disabled children (usually together with family members) stayed in Ajoya as PROJIMO guests for a total of 800 child/days.

- 90 villagers (55 adults and 35 children) volunteered with the program for a total of roughly 2000 person/days.

- 364 pieces of orthopedic, therapeutic or related equipment were produced or repaired by PROJIMO workers at an approximate cost (materials and labor) of 150,000 pesos (US$1000.00).

The equivalent cost of like equipment in the cities would run approximately 1,500,000 pesos (US$10,000) or roughly 10 times as much.

Equivalent cost in U.S.A. would be around $50,000--or 50 times the PROJIMO costs. Equipment produced included:

		pesos
80	braces (55 below knee, 15 above knee, 10 other)	10,000 x 80 = 800,000
25	seating devices (15 special chairs many with wheels, 6 sitting boxes, 4 special cushions)	5,000 x 25 = 125,000
12	wheelchairs (10 repaired or rebuilt, 2 rough terrain chairs designed and built)	30,000 x 2 = 60,000 2,000 x 10 = 20,000
15	other mobility devices (6 scooters, 2 straddle carts, 2 pushcarts, 6 walkers)	3,000 x 15 = 45,000
60	crutches of different types (mostly rebuilt)	2,000 x 60 = 120,000
50	shoes or sandals orthopedically adapted	2,000 x 50 = 100,000
20	pieces of playground equipment	1,000 x 20 = 20,000
15	educational or therapeutic toys	500 x 15 = 7,500
4	standing frames or boards	5,000 x 4 = 20,000
2	balance boards	1,000 x 2 = 2,000
10	exercising devices	1,000 x 10 = 10,000
15	finger, arm, or hand splints	1,000 x 15 = 15,000
12	contracture correcting devices	5,000 x 12 = 60,000
1	body corset	10,000 x 1 = 10,000
35	flexikins for measuring contractures	500 x 35 = 17,500
3	parapodia (walking frames)	5,000 x 3 = 15,000
1	communication board	1,000 x 1 = 1,000
4	special toilets	5,000 x 5 = 20,000
364		1,468,000 pesos

1,500,000 pesos = US$10,000

COMMUNITY HEALTH
LIBRARY
AND
INFORMATION
CENTRE
BANGALORE

• 354 orthopedic castings were done on a total of 25 persons (5 adults) including:

190	serial casts to correct contractures (in 8 children and 1 adult).
90	serial casts to correct club feet (in 3 children).
12	fractures
2	dislocations
60	casts for making braces and limbs
354	

Cost to PROJIMO for casting: ..... 15,000 pesos (US$ 1,000).
Lowest cost in a city charity hospital,
where a family pays 2,000 pesos/cast
(5 times as much): ..... 780,000 pesos (US$ 5,000).
Cost in U.S.A. at $40.00/casting: ..... US$15,000.

• 10,000 hours of family consultation/physical therapy, nursing care. Cost to PROJIMO (not counting visiting therapists' travel expenses) at 75 pesos/hr.:

750,000 pesos or ..... US$5,000.00

Travel costs of therapists and
children referred to hospitals .....US$2,500.00

$7,500.00

Approximate cost for Mexican professional therapist for equivalent services at 1000 pesos/hr.: 10,000,000 pesos
($65,000 or nine times as much as the PROJIMO cost).

Approximate cost for same services in U.S.A. at $50.00/hr.:
($500,000 or 60 times as much as the PROJIMO cost).

• 1,500 person/days of room and board to visiting children and families cost PROJIMO and/or the families 150,000 Mexican pesos or .....US$1,000 ($800 of it paid by visiting families).

Cost for equivalent in cities at 1,000 pesos/day:
= 1,500,000 pesos or ..... US$10,000.
Cost for equivalent in the U.S.A at $20.00/day .....$30,000.

-- 0 --

Total costs to PROJIMO for all the services provided were approximately: US$10,000. Of these costs about $600 were recovered from what families paid for services and equipment.

Other major costs to PROJIMO include:

Travel expenses of advisers	$1,500
Travel, 25 children and 5 adults to Shriners	1,000
Building of new quarters and restoration of old	2,000
Therapy pool	200
Machinery and equipment	2,000
Cost of room, board and salaries for apprentice workers	2,000
Cost of travel and living expenses of workers in the training programs in other places	1,000
Other	300
	US$10,000

Total costs to PROJIMO for one year: $20,000.

In addition to this $20,000.00, the Hesperian Foundation has spent $7,160 for development of slide shows and written materials.

Costs for equivalent services and equipment in Mexican cities:

Services and orthopedic aids	$80,000.00
Room and board	10,000.00
	$90,000.00

Costs for equivalent in U.S.A.:

Services and orthopedic aids	$565,000.00
Room and board	30,000.00
	US$595,000.00

SUMMARY OF COST EFFECTIVENESS Fiscal year Sept. 1982 to Sept. 1983

PROJIMO spent approximately $US10,000 on providing services and equipment to 274 persons (average $36.00 per person for an average of 36 hours of care and 1 orthotic appliance and one plaster cast per person).

To provide this same amount of service and equipment by professionals in a Mexican city would cost about $US80,000.00 or 8 times as much.

To provide the same amount of service and equipment in the U.S.A. would cost about US$565,000.00 or 56 times as much!

The differences in cost of services and equipment is striking. However, when it comes to services, the difference in cost for the amount of benefit received may not be as great as the difference in cost per hour. In so far as the team is still learning and is less efficient in its use of time than are most professionals, things take longer. However, the extra time taken may help families to learn recommendations and therapy at a slower pace that makes things easier to remember. (Also the village rehabilitation workers explain things in the common people's language, not 'medicalese'. This takes longer, but makes for better communication).

Any way you look at it, the PROJIMO team is providing a lot for the money. A great deal of benefit has been provided: for the disabled children, for their families, for the team of disabled village workers, and for the local community.

In addition, through slide shows, correspondence, and visits to other programs working (or considering working) with disabled children, we hope that the PROJIMO experience may bring benefit to many corners of the earth. The forthcoming rural rehabilitation manual should also help in this process.

NUMBERS AND TYPES OF DISABILITIES SEEN AT PROJIMO
SEPTEMBER 1982 to JUNE 1983

(Note: These figures do not represent all the disabled persons in any given area, but rather those who came to the rehabilitation center.)

PRIMARY CONDITION	Numbers seen	M	F	Children	21+	Related Problems			
						Contractures	Scoliosis	Seizures	Retarded
POLIO	70	45	25	63	7	37	17		
CEREBRAL PALSY	65	41	24	57	8	16	1	23	27
SPINA BIFIDA	10	6	4	10		1	1		
JUVENILE ARTHRITIS	6	2	4	4	2	3			
ARTHRITIS (ADULT)	5	2	3		5				
RHEUMATIC FEVER	1	1		1					
PARAPLEGIA	8	4	4	5	3	1			
QUADRIPLEGIA	2	2			2				
STROKE	5	1	4		5				
DOWN'S SYNDROME	4	2	2	4					4
EPILEPSY*	4	1	3	4				4	2
AMPUTATIONS	4	3	1	2	2	1			
MUSCULAR DYSTROPHY	3	3		2	1			1	1
ARTHROGRYPOSIS	3	3		3		2			
HEART MURMUR/DEFECT	3	3		3					
DEAFNESS*	4	3	1	3	1				1
BLINDNESS*	3	2	1	2	1				
CLUB FEET	3	2	1	3		1			1
FLAT FEET	2	1	1	2					
BURN DEFORMITIES	3	1	2	2	1	1			
GENERAL MUSCLE WEAKNESS	2	1	1	2		2			
MULTIPLE SCLEROSIS	2	1	1		2			2	
TUBERCULOSIS OF BONES	2	1	1	1	1				
LEPROSY	1	1		1					
	215	132	83	174	41	65	19	30	36

* Many more persons with epilepsy, blindness, deafness, scoliosis, and behavior disturbances were seen, but have been recorded under their primary problem (often cerebral palsy). See seizure and scoliosis under 'related problems'.

PRIMARY CONDITION	Numbers seen	M	F	Children	21+	Contractures	Scoliosis	Seizures	Retarded
MENIERE SYNDROME	1		1		1				
DEEP FUNGUS	1	1			1				
BURN DEFORMITY	1	1			1	1			
VITILIGO	1		1	1					
SHINGLES	1	1			1				
LUPUS ERYTHMATOSIS	1		1		1				
EXTROPHY OF BLADDER	1		1	1					
PELVIC TUMOR	1	1			1				
INGUINAL HERNIA	2	2		2					
SCOLIOSIS*	2	1	1	2			2		
CLEFT LIP AND PALATE	2	1	1	2					
BIRTH INJURY LEGS, ARMS	2	1	1	2					
TENDONS SCARRED TIGHT	1	1		1					
JOINTS FUSED	1		1		1				
OSTEOMYELITIS	2	1	1	1	1				
LIMB BIRTH DEFECTS	3	2	1	2	1				
SHORT LEG	1	1		1					
FACE PARALYSIS	2	1	1	2					
SCIATICA/SLIPPED DISK	3	3			3				
CHRONIC BACK PAIN	2		2		2				
CHRONIC KNEE PAIN	2	1	1	1	1				
WRY NECK (TORTICOLIS)	1		1	1					
BEHAVIOR DISTURBANCE*	2	2		1	1				
DISLOCATED HIP	1		1	1					
DISLOCATIONS BY TRAUMA	3	2	1	3		1			
CUT TENDONS	1	1		1					
TORN LIGAMENTS	1	1		1					
FRACTURES	13	4	9	6	7				
TOTAL, THIS PAGE	55	29	26	32	23	2	2		
GRAND TOTAL	270	161	109	206	64	67	21	30	36

Problems and Possible Solutions.

At the close of PROJIMO's first unofficial year, several long evaluation discussions were held among the staff, visiting therapists and advisers, together with a few family members of disabled children and some local villagers. Among other things, the following problems and proposed solutions were discussed.

Problem: Skilled able-bodied craftsmen who were sent to learn special skills, now demand higher earnings and are reluctant to teach others. This problem has already been discussed (p. 41).

Proposed solutions: (1) Have other, lesser skilled but socially more committed members of the team trained in the special skills so they can replace the 2 craftsmen. (This has already been started, both in wheelchair making and prosthetics.)

Problem: Record keeping inadequate. This has already been discussed (p.24).

Proposed solutions: (1) Simplify record sheets. (2) Have one person who writes fairly clearly act as receptionist, write address and take general history before the consultation begins. (3) Have review and practice sessions at record keeping.

Problem: Not enough time for teaching sessions at PROJIMO. Attempts have been made to set aside time for study sessions when David Werner or visiting therapists are present. But the arrival of more disabled children and pile up of work often cause study sessions to be cancelled. The group feels that such study time is important, especially to review and learn to use the materials from the new Rural Rehabilitation Manual.

Proposed Solutions: (1) Make a daily schedule and stick to it. Schedule study time early in the day so that when things pile up study time is not cancelled. (2) Try to have therapists stay for more days when they visit (present visits are 3-4 days) so that fewer children can be seen daily and more time is available for teaching. (3) Take care to limit number of children invited back for rehabilitation when therapists are coming.

Problem: Visiting therapists sometimes 'take charge' and stop teaching. The main function of visiting therapists is to teach the village rehabilitation workers. This is mostly done by their seeing disabled children together with the rehabilitation workers. Ideally, the rehabilitation worker examines the child, makes a diagnosis, decides what is needed, and discusses all this with the therapist. The therapists play a background role, giving approval, suggestions, and criticism as needed.

What often happens, however, is that so many disabled children are waiting, and there is so much to do, that the therapists begin to take over and the rehabilitation workers take a more secondary role. Part of the problem is that the most capable workers in consultation and therapy are also the most capable workers in making braces and therapy aids. So often they are trying to do two jobs at once.

Proposed solutions: (1) Have village rehabilitation workers take a complete history, complete an examination, and decide what they think should be done before the visiting therapists open their mouths. Next have the rehabilitation workers 'present' the child and her problem to the therapist, explaining the situation and proposed course of action. Finally, the therapist gives suggestions. A firm understanding about this approach needs to be agreed upon ahead of time. (2) Work hard to get more rehabilitation workers trained, both in consultation/therapy and orthotics making.

Problem: Crowded workshop--hard to get what you need. Various activities go on in the workshop--sometimes all at the same time: brace-making, limb-making, aid-making, wheelchair-making, sandal-making, etc. The workshop is on a long narrow porch where 2 wheelchairs have trouble passing. Tools and supplies get mixed up. It is simply too crowded!

Proposed solutions: (1) Build a new workshop area, designed so wheelchairs can pass. (2) Divide workshop space into areas according to different kinds of work being done. (3) Make sure tools are hung low on walls or are kept where they can be easily reached by persons in wheelchairs. (4) Make work benches low--at the right height for wheelchair users.

Problem: Visiting families sometimes sleep on floor of center. Although room and board with cooperating local villagers is always available at low cost for PROJIMO visitors, some families are so poor that they ask to stay in the Rehabilitation Center. Often they sleep on the floor because there are too few cots.

Proposed Solutions: (1) (Short term) Provide more cots. (2) Build a low-cost (mudbrick) guest house. The suggestion was made that this 'demonstration house' have many features built-in that make it easier for disabled persons: level entries for wheelchairs, a large toilet area with bars and supports, kitchen utensils that are easy to hold for persons with hand problems, cots the level of wheelchairs for easy transfer, level firm floors (but not too smooth) etc. Thus the guest house would provide ideas to the visitors for making low-cost adaptations in their own homes.

Problem: A few families never return for braces or aids that have been specially made. There may be several reasons for this. Cost (of transportation, if not the aid) may be a factor. Also, since some children are taken to California for surgery, some parents obviously arrive with a dream that the child's disability will disappear with surgery or 'Gringo magic'. When they are told their child can be best helped by braces or aids, they are heartbroken--although they are often too polite to admit it. They politely endure the measurements and castings, leave, and never come back. This has happened in about 6 cases. It is not only unfortunate for the children but demoralizing for the workers who put a lot of care into preparing the braces.

Proposed solutions: (1) Try to identify the families that have come with the hope that their child will be 'cured'. Visiting therapists suggest that everyone be asked "Why did you come? What is it you want for your child? What is it you would like us to do?" This opens the doors for discussion, better understanding, and parents' participation in deciding what to do for the child. (2) Ask for at least a token payment for braces and equipment before they are made. This will help guarantee that the family comes back for them. (3) If a family does not return for a brace, try to deliver it, or at least visit the family to see what the problem is. (For example, sometimes a mother brings a child for a first visit, then the father will not let her come again.)

Problem: Some families who could pay more pay very little. For families who obviously are extremely poor PROJIMO not only reduces charges for services and equipment to a token charge only, but sometimes contributes the living costs for families who need to stay for several days in Ajoya. And so the word gets around. Other families arrive who are in a better position to pay, but say they did not bring money or cannot afford to pay.

Proposed solutions: (1) Put up posters and perhaps provide handout sheets explaining PROJIMO goals, financial limitations and the need of families to help cover costs. (2) Inform families of the actual costs to the project for services and equipment provided, and ask those who can afford it to cover this cost--plus some extra if possible to help cover costs of those who cannot pay the full amount. (3) Make a 'donation box' for services available in which people can contribute according to their abilities and consciences. (This has already been done.)

Problem: Local tax collector demands bribe from PROJIMO. In order to get a permit for an acetylene tank (for welding) PROJIMO had to register as a 'wheelchair-making shop'. Even though the wheelchair making is still experimental and no chairs have yet been sold, the state tax collector demanded 30,000 pesos in taxes from Roberto. Finally the tax collector agreed to accept a 15,000 peso bribe to issue a statement that no income had been made (a true statement that should have been issued free). Of course Roberto should not have paid the bribe, but by the time the others heard about it, it was done.

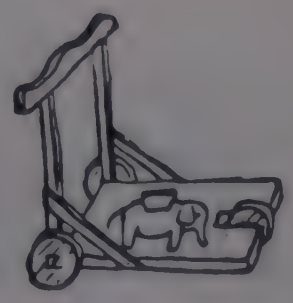
Proposed solutions: (1) The group, instead of keeping the bribe a secret, talked openly about how the tax collector had robbed them. Since a witness had seen Roberto give her the 15,000 pesos, the collector later made out a false tax receipt for the 15,000. But in this she trapped herself, since now PROJIMO has 2 receipts for the same period, one saying there was no income and therefore no tax, and the other charging a tax. (2) In addition, PROJIMO has called on the help of Los Pargos, the organization of families of disabled children in Mazatlan. One of the Pargos sponsors is a friend of the wife of the governor of the state. The governor's wife has agreed to see that the tax collector does not cause PROJIMO any more problems. (3) In the future, do not pay bribes--or at least not before discussing it with the whole group.

Problem: Many children come long distances and from cities. Ironically, half the children now seen at PROJIMO village center come from the cities of Mazatlan and Culiacan, 80 and 120 miles away. (This speaks of the great unfilled need in the cities as well.) The long distance families come creates several related problems: (1) Home visits as well as neighborhood work in the community of the families becomes very difficult. (2) Visits to PROJIMO by families are costly (travel expenses) and less frequent. This makes follow-up more difficult and puts pressure on rehabilitation workers to finish braces and aids the same day (which means teaching sessions are missed, etc.).

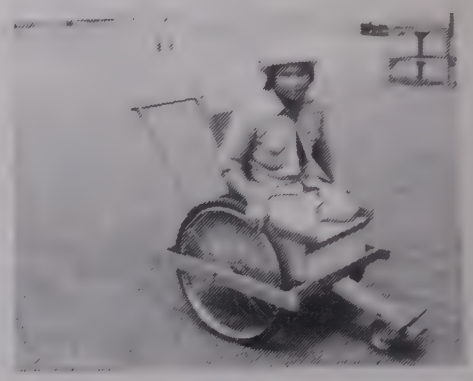
Proposed solutions: (1) Help families of disabled children in distant communities to organize, plan trips to PROJIMO together, visit each other's homes, etc. (2) Hold periodic 'outreach clinics' (travel by bus) in the cities and larger villages--at least for follow-up. (3) Try to train selected persons (perhaps disabled youths) from different distant communities to apprentice with PROJIMO for a period and then serve their own communities as 'rehabilitation assistants'. (4) A long-term goal of PROJIMO is for the program to spread. Many disabled young people from neighboring areas after they work with PROJIMO for a period of time (2-3 years?) may eventually set up their own 'satelite centers' in their own towns. What is most important here is to provide a support system (often miscalled supervision) that will help guarantee (a) quality of service, and (b) low-cost services (the philosophy of working for the people, not the money).

Problem: There are still no adequate services for children who are retarded, mentally disturbed, deaf or blind. PROJIMO began with a focus on physical disability. Physical disability seems to be most common as well as most easy to do something about at the village level. However, many children with other disabilities are being brought to PROJIMO and the team is not well prepared to deal with these other problems.

Proposed solutions: (1) As mental retardation is quite common, give priority to learning about this. At present David Werner is working with therapists on simplified guidelines for mental retardation and developmental delay. (2) The next biggest problem is deafness. Contacts have been made with persons experienced with working with deaf children, who may be able to visit Ajoya and help work out a beginning program. (3) At present there are no plans for a special program for the blind--except a proposed visit by Sophie Levitt (from England) who is an expert on cerebral palsied children who are blind. Families with such children will be asked to bring their children to PROJIMO during Sophie's visit. (4) For children with severe behavior problems (often retarded) programed 'behavior modification' is being investigated.



Problem: The present models of rough terrain wheelchairs still cost too much. Although the folding metal tubing chairs are of high quality, and ideal for rough terrain, they still cost about 1/2 to 2/3 the price of a commercial wheelchair in Mexico (which are 1/2 the price in the USA). This is still far more than many poor families can afford.



Proposed solutions: Experiment with wooden and non-folding wheelchairs to see if a rugged, rough terrain model can be made at low cost. Another advantage to the wooden model is that it could be made by village carpenters. (Most villages have carpenters but few have welders.) Designs of wooden wheelchairs in other countries are being investigated.

Problem: Lack of confidence for decision-making--especially for courses of therapy. Everyone agrees that the village rehabilitation workers are stronger on technical production--making aids, braces, etc.--than on the 'clinical' skills: evaluating a child's disability and deciding what needs to be done, especially when it comes to decisions about physical therapy. For this reason the workers often ask parents to bring children back when the therapists are visiting, rather than to begin a course of action for themselves. In part, this is a wise precaution. But in part it results from a lack of self-confidence. For when asked, the rehabilitation workers often come up with appropriate answers.

Proposed solutions: (1) Focus training on the process of consultation, problem-solving and decision making about what needs to be done. (2) Provide more training in principles of child development and physical therapy, helping them to make decisions based on what they observe. (3) Be sure that rehabilitation workers are always asked what they think should be done before the visiting professionals give their opinions. Therapists and advisers should help the rehabilitation workers gain greater confidence. (4) Praise the workers' ability when they come up with reasonable answers. Encourage inventiveness and use of common sense in problem-solving.

Problem: Often visiting therapists seem to disagree on their recommendations of therapy, or to criticize an approach of a previous therapist. This tends to confuse and upset the rehabilitation workers.

Proposed solutions: Help rehabilitation workers realize that often there are no 'right answers'--especially when it comes to therapy. Everyone, professional and lay, tries to find the best approach for the individual child. Sometimes a mother (who has more experience with the child) will come up with better suggestions for therapy, or how to make the therapy acceptable to her child, than will the therapist. Often therapists do disagree. Rehabilitation workers need to realize that their own observations, common sense, experience and decisions also have value. If they err, they do so usually on the side of being over-cautious--which is probably good.

Problem: Little possibility for low-cost orthopedic surgery in local hospitals. Up to now PROJIMO has had to take children out of the country for orthopedic surgery because it is too expensive in local hospitals (for those not insured by Seguro Social).

Proposed solutions: So far, one orthopedist has offered (and begun) to donate his surgical services. However, PROJIMO must actively seek other possibilities within the country for low-cost orthopedic hospital care. Eventually, families of the disabled must organize to insist on their rights.

Problem: More need for prevention of disabilities--especially polio and secondary disabilities like contractures. In western Mexico, polio is probably still the first cause of physical disability in children (followed closely by cerebral palsy). The government has a vaccination program, but this breaks down especially in remote rural areas and in city slums. Spoilage of vaccines is a big problem. It is estimated that 1/3 of polio vaccines given to children are useless because they have not been kept adequately frozen. Ironically, in the mountain area where Project Piaxtla's village health workers have carried out a community-based vaccination program, there have been almost no new cases of polio in the last 16 years. Most of the children with polio whom PROJIMO sees, however, come from outside this mountain region. Many come from the slums of the cities--areas where PROJIMO has little possibility for direct action. Also, because PROJIMO has no community program in these faraway areas, children with polio and other disabilities are often brought late, after secondary disabilities and deformities such as contractures and spinal curvature are already advanced.

Proposed solutions: (1) Look for ways to 'reach' distant communities with an effective preventive campaign. Many parents, particularly in slum areas, do not vaccinate their children because of rumors that the vaccines themselves may cause polio, or sterilize their children. The parents of children with polio can be encouraged to be 'prevention promoters' in their communities, by explaining to neighbors and friends:

(a) the importance of making sure their children get vaccinated.

(b) the importance (in preventing polio) of not injecting a small child with any medication unless absolutely necessary, and never when the child has signs of a cold or the flu. (See page 50.)

(c) the importance of taking children with polio and other disabilities to a rehabilitation center soon after they become disabled, before contractures and other complications develop.

(2) (Long term) Duplicate or extend the PROJIMO rehabilitation program with a community rehabilitation worker or satellite center in key locations, including more distant villages and the city slums.

Role plays and farm workers' theater are effective forms of education for prevention of disabilities.

RELEARNING TO MOVE AND TO SMILE--THE STORY OF TERESA'S REHABILITATION

To close this statement on Project PROJIMO, it seems fitting to tell Teresa's story. It is not really a success story--or not yet. For Teresa's rehabilitation has been a long slow struggle; she still has a very long way to go. We tell her story because Teresa is the child who has spent the most time with PROJIMO (7 out of the first 12 months). She is the child who has most tested, frustrated, and enlarged the team's capacity for personalized aids, creative adaptations, therapy and love.

To help straighten Teresa's severe wrist and knee contractures, visiting physical therapists made splints out of a costly orthopedic plastic.

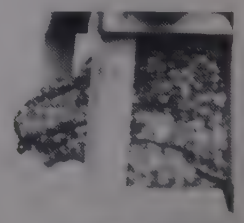
Teresa has suffered from juvenile rheumatoid arthritis since age 7. When her mother first brought her from a distant village at age 14 her body had long since stiffened into the shape of a chair. The only thing that she moved was her eyes. Her joint pain was so great that she spent every night crying. Years before, a doctor had prescribed aspirin, but in time she had developed such stomach distress that she had stopped taking it.

Teresa had lost hope. Once she had been a cheerful, ordinary child. She had completed 3 years of school. Now she spent her life sitting silently in front of a television. She almost did not speak, answering questions with single words. It was weeks before the PROJIMO team saw her smile.

The PROJIMO team at once put her back onto aspirin, but with care that she take it with meals, lots of water, and an antacid. Then they began a long, slow process of rehabilitation, which is documented here in these photos.

After trying their own splints, the therapists agreed that the stretching splints a village rehabilitation worker had already made worked better. They are made from old plastic buckets and strips of tire tube...at almost no cost.

As Teresa began to regain movement, the team designed an adjustable sitting walker for her, with shoulder supports and a saddle seat that can be raised.



Teresa was improving steadily. Unfortunately, when she returned home for Christmas she fell ill with dengue (break bone fever) and nearly died. Her family stopped both exercises and medication. When she returned 6 weeks later she was as stiff and bent as when she had first come. She was so depressed she spoke to no one, not even her parents. The team began her rehabilitation all over again.

This time the rehabilitation workers decided to straighten her contracted legs through a series of casts.

Village children volunteered to assist her with activities that would help her regain use of her hands--and lift her spirit.

Here a child with cerebral palsy plays with Teresa by having her kick a ball. This helps strengthen the muscles that straighten her legs.

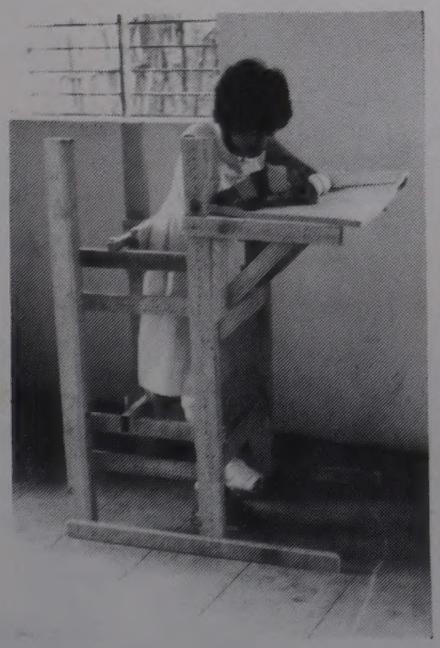
Here Conchita--a girl with cerebral palsy who joined the PROJIMO staff to become Teresa's friend and assistant in therapy--helps her with foot exercises.

A visiting physiotherapist teaches Javier how to help Teresa increase movement in her stiff neck.

Teresa still has a long way to go before she is fully functional and independent, but she has come a long way. Now she spends an increasing amount of time back in her village with her family. Together with her family, she is taking more responsibility for her own therapy and continued improvement. The village team of PROJIMO have helped her gain new understanding and use of her body, new friends, and a new more hopeful view of herself.

Gradually Teresa began to take interest again in life. She enjoys swinging.

Finally with the serial casting, Teresa's knees and wrists became fairly straight.



So the team made an adjustable standing frame for her.

They also built a 'therapy pool', which Teresa has greatly enjoyed. She has begun to improve more rapidly, both in body and spirit.

Here Teresa is learning to walk in a special walker made by the village team--but she still needs her homemade leg-supports.

At last Teresa is able to walk with a regular walker and without leg braces.

With the help of the PROJIMO team, Teresa has a new happier outlook on life--and a brighter future.

Some of the photographs on pages 1, 11, 12, and 64 are by Richard Parker.
Some of the photographs on pages 10, 11, 13, and 39 are by Bill Bower.
The rest of the photographs, drawings, and text are by David Werner.

Some Basic Principles for Rehabilitation of Disabled Children

1. The main objective of rehabilitation is to achieve the greatest possible degree of self-reliance and dignity—both for the disabled child and his or her family.

2. The primary responsibility of health workers and therapists is to share their knowledge: to teach the immediate family how to help the child become as self-reliant as possible.

3. Avoid creating dependency. Provide only as much assistance as is necessary to allow the child to do the maximum amount for herself.

4. Include the disabled child as much as possible in meals, housework, school, games, discussions, festivals.

5. Recognize and encourage the disabled child's strengths, rather than just looking at his weaknesses.

6. A few simple, low-cost homemade aids can often help disabled children become more independent.

7. Adapt technology to the family's economic and geographic reality. Where possible, use local materials for crutches, walkers, and other rehabilitation aids. Invite the family—and child—to take part in making them.

8. Help families to learn the principles of therapy, and to invent ways to apply them in their day-to-day activities with the child.

9. The best therapy is that which children do for themselves, because it is fun.

10. Find ways that the handicapped child can help out in the home—and eventually in society.

11. Simplified, community-based rehabilitation should be an essential part of primary health care everywhere.